# Exploring Rural Resilience Through Cultural and Geospatial Contexts

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A Dissertation presented to the Graduate faculty of the University of Virginia in candidacy for the degree of Doctor of Philosophy

Department of Nursing

University of Virginia May, 2022

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# **Dedication**

To my husband, Tim Miller, who has spent most of this time deployed. I'll see you soon.

## Acknowledgements

I would like to extend my sincere gratitude to my committee members, Drs. Pam DeGuzman, Virginia LeBaron, Jamie Zoellner, and Kathleen Porter for all their contributions and support of my dissertation work. To my advisor, Dr. DeGuzman, since my interview for the PhD program at UVA you have mentored me with patience, kindness, and brilliance. Looking back at some of the work I did my first semester at UVA, I am amazed at the extent of what I've learned from you. Most importantly, you've taught me to love the work I do. To Dr. LeBaron, thank you for your extensive mentorship and your constant support. Whenever we spoke about a paper or grant I submitted, you always said "when this is accepted," and I now talk that way about my own work. To Dr. Porter, thank you for your expertise in rural survivors and rural culture. Your knowledge added depth and was critical for analysis. My work is always improved after your feedback. To Dr. Zoellner, I think every committee member has heard me say "I want to be like Dr. Zoellner when I grow up." The first time you spoke to my cohort, you said "success is failure without loss of enthusiasm." Ever since, I have had that quote on a sticky note on my computer to see every time I submit a paper or grant. Thank you for your mentorship in building my program of research, and guidance in my professional development.

In gratitude to my patients, and to all study participants, thank you for sharing your stories with me. To my dad, for inspiring me to a career of service. A very special thank you to my mom, especially for helping me the last few months. To Oliver and ZeeZee, who remind me to live in the moment each day. To Megan McCusker, for your support and for always knowing when to take me out of the library. To Luisa, Courtney, Elissa, and Heather, for your friendships and giving me a place to rejuvenate. Finally, to my husband, for first asking "how is your dissertation going?" when he calls, even though he's across the world and in a combat zone.

#### Abstract

Rural cancer survivors experience worse quality of life (QoL) and greater cancer-related distress (CRD) when compared to urban survivors. These cancer disparities are attributed to poor healthcare access and culturally inappropriate care for rural cancer survivors. Rural survivors travel an average of 60 minutes to reach a healthcare facility, and healthcare providers may perceive rural cultural norms, such as spirituality, to be a barrier to providing care. One way nurses can improve rural survivors' QoL and reduce survivors' CRD is by promoting resilience. Resilience improves QoL and reduces CRD in cancer survivors. Therefore, the goals of this dissertation are to 1) explore the cultural and geographic contexts of resilience in rural cancer survivors, and 2) inform the development of future interventions that are geographically-accessible and culturally appropriate. To achieve these goals, three manuscripts are presented.

In the first manuscript, I develop an evidence-based conceptual framework for *rural* resilience in cancer survivors. I use the Walker & Avant method to construct an evidence-based conceptual framework of rural resiliency for cancer survivors grounded in three domains of rural culture: spirituality, cultural norms, and social capital. These domains impact a cancer survivor's status on the continuum of resilience-distress, leading to either negative or positive psychosocial outcomes.

In the second manuscript, I use a multi-method approach using descriptive qualitative interviews and a quantitative survey, the *Telemedicine Satisfaction and Use Questionnaire*. Three themes were extracted from the qualitative interviews: rural cancer survivors trust oncology nurses with their distress experience, an oncology nurse telehealth visit increases survivors' access to information and education, and rural cancer survivors overcome technology barriers to speak with an oncology nurse. Quantitative findings indicated high satisfaction with

the nurse-patient relationship over telemedicine and lower satisfaction with using telemedicine equipment to connect to a visit.

In the third manuscript, I use semi-structured interviews and thematic analysis guided by the conceptual framework of *rural resilience* to identify facilitators and barriers of resilience in rural cancer survivors, and to identify community locations for future interventions. Three themes emerged from the data: 1) spirituality facilitates resilience in rural cancer survivors, 2) rural cancer survivors accommodate the cultural norms of fatalism, mistrust of providers, and cultural differences to maintain resilience, and 3) rural cancer survivors strengthen resilience through social capital on virtual platforms in the context of COVID-19. We found that rural cancer survivors are seeking to strengthen resilience and reduce CRD through virtual platforms in the context of COVID-19, despite the challenge of poor broadband. We also found that spirituality facilitates resilience in rural cancer survivors, while rural cultural norms of fatalism, mistrust of local hospitals, and cultural differences are barriers to resilience.

I conclude that the evidence-based conceptual framework of rural resilience can guide nursing interventions promoting resilience in rural cancer survivors, and that future interventions should be implemented on virtual platforms. The findings of this dissertation can be used to inform nursing interventions that support resilience, improve QoL, and reduce CRD.

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# Chapter 1

### Introduction

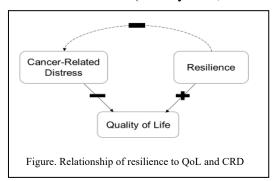
There are approximately 3 million cancer survivors living in rural US communities who experience greater cancer-related distress (CRD) and worse quality of life (QoL) compared to urban survivors (Weaver et al, 2013). These rural cancer disparities are attributed to poor healthcare access and culturally-inappropriate care, which impact the health-seeking behaviors of rural residents (Farmer et al, 2012). Rural cancer survivors experience poor access to health care due to local hospital closures, provider shortages, and long travel distances to care (Weaver et al, 2012). Due to poor healthcare access, rural cancer survivors are often unable to travel to their post-treatment follow-up appointments. It is necessary to adapt interventions promoting QoL and reducing CRD to be accessible for rural communities (Schootman et al, 2013). One way to make these interventions accessible is to utilize virtual platforms. Interventions tailored to meet rural survivors' geographic context, such as a nurse-led videoconferencing intervention, may be effective at reducing CRD (DeGuzman et al, 2020). However, little is known about rural survivors' experiences using virtual platforms to manage CRD and improve QoL.

Rural culture also impacts cancer beliefs and behaviors (Rawl et al, 2019). Healthcare workers may perceive rural culture a barrier to providing care, and therefore don't demonstrate cultural sensitivity to rural patients (Farmer et al, 2012). Rural cancer survivors do not consider many cancer interventions to be culturally-relevant (Dulko et al, 2018), which may reduce their health-seeking behaviors (Farmer et al, 2012). However, culturally-relevant interventions, such as faith-based nursing for cancer care, are accepted by rural patients (Zahnd et al, 2018). In rural communities, faith is associated with community, support, and identity, making spirituality an important cultural value to consider when providing healthcare (Reid-Arndt & Cox, 2010). A

comprehensive understanding of the rural cultural context is needed to inform future interventions for survivors (LeBaron, 2018).

Interventions targeting *resilience* are ideal for improving QoL and decreasing CRD while being culturally-relevant and geographically-accessible (Deshields et al, 2016). Cancer survivors with higher levels of resilience experience increased QoL and decreased CRD (Dooley et al;

2017; **Figure**). However, there are few interventions targeting resiliency in rural cancer survivors, and these may not address the rural cultural and geographic contexts (Bernacchi et al, 2021). The goals of this dissertation are to 1) understand resilience within rural



cultural and geographic contexts, and 2) inform future interventions promoting resilience to be geographically-accessible and culturally-relevant.

The goals are addressed in three manuscripts (Chapters 3-5). Goal one is addressed in Chapters 3 and 5. In Chapter 3, I discuss an evidence-based conceptual framework for *rural resilience* in cancer survivors, which incorporates the impacts of rural culture. In Chapter 5, I identify cultural facilitators and barriers to resilience in rural cancer survivors. Goal two is addressed in Chapters 4 and 5. In Chapter 4, I discuss the experiences of rural cancer survivors using a telehealth intervention to manage CRD. In Chapter 5, I identify rural survivors' priority locations for geographically-accessible interventions promoting resilience. The findings of this dissertation inform the development of future interventions promoting resilience, improving QoL, and reducing CRD that are geographically accessible and culturally-relevant.

## **Chapter abstracts**

In Chapter 2, I present my dissertation proposal. This includes intended recruitment and sampling techniques, data collection and analysis methods, and plan for dissemination.

In Chapter 3, I provide a comprehensive understanding of resilience, and the relationship of resilience to OoL and CRD (referred to in this chapter as psychosocial distress), within rural cultural and geospatial contexts. I identify the concept of rural resiliency in cancer survivors in the nursing literature and propose a conceptual framework that may help nurses leverage resilience to improve rural survivorship care. I use Walker & Avants' concept analysis method to direct the selection and analysis of research articles published between 2000 and 2020 that focused on cancer survivors residing in rural communities. I identify a definition, antecedents, consequences, attributes, and empirical referents, and related terms. I develop model, contrary, and borderline case examples. A novel conceptual framework incorporating these attributes is proposed. The conceptual model of rural resiliency for cancer survivors is grounded in three domains of rural culture, each with attributes that may impact rural resiliency: spirituality, cultural norms, and social capital. These domains impact a cancer survivor's status on the continuum of rural resilience-psychosocial distress, leading to either negative or positive psychosocial outcomes. This manuscript was published by the Online Journal of Rural Nursing and Healthcare in 2021.

In Chapter 4, I discuss a geographically-accessible, nurse-led telehealth intervention to address CRD in rural cancer survivors. I describe rural survivors' experiences of participating in a nurse-led telemedicine visit for addressing cancer-related distress. Twenty-five rural-dwelling post-treatment adult head and neck cancer survivors were recruited from a cancer center clinic affiliated with an academic health system serving a rural catchment area in the Southeastern U.S. I use a multi-method approach using descriptive qualitative interviews and a quantitative survey,

the *Telemedicine Satisfaction and Use Questionnaire*. Three themes were extracted from the qualitative interviews: rural cancer survivors trust oncology nurses with their distress experience, an oncology nurse telehealth visit increases survivors' access to information and education, and rural cancer survivors overcome technology barriers to speak with an oncology nurse.

Quantitative findings indicated high satisfaction with the nurse-patient relationship over telemedicine and lower satisfaction with using telemedicine equipment to connect to a visit. I found that rural cancer survivors are willing to overcome technology barriers to discuss cancerrelated distress with a nurse over telemedicine. Although they may be willing to be open and vulnerable about distress with an oncology nurse, they are less likely to accept a referral to another provider for psychosocial care. Nurses can incorporate warm handoffs to increase psychosocial referral uptake for rural survivors. This manuscript is currently under review at *Oncology Nursing Forum* (submitted 2.21.2021)

In Chapter 5, I identify facilitators and barriers to resilience in rural cancer survivors, guided by the cultural domains from our conceptual model of *rural resilience*. I also identify priority locations for interventions targeting resilience in rural cancer survivors. Seven posttreatment rural cancer survivors, four caregivers of rural cancer survivors, and one rural cancer survivor who also identified as a caregiver were recruited from Southwest Virginia. Data was analyzed using thematic analysis using line-by-line coding. The inductive development of comparative themes and meanings were guided by the conceptual model of rural resilience.

Three themes emerged from the data: 1) spirituality facilitates resilience in rural cancer survivors, 2) rural cancer survivors accommodate the cultural norms of fatalism, mistrust of providers, and cultural differences to maintain resilience, and 3) rural cancer survivors strengthen resilience through social capital on virtual platforms in the context of COVID-19. Understanding

the role of spirituality, cultural norms, and social capital will help nurses develop and implement interventions strengthening resilience in rural cancer survivors. Nurses can support resilience in rural survivors by incorporating a spiritual assessment into survivorship care, and guiding survivors to virtual support groups. This manuscript is prepared to submit to *Oncology Nursing Forum* pending feedback from the dissertation committee.

In Chapter 6, I summarize the overall dissertation findings, and discuss their clinical implications. This chapter also includes future directions for this program of research.

# **Chapter 1 References**

### References

- Bernacchi, V., Zoellner, J, DeGuzman, P. (2021). Rural resilience in cancer survivors: conceptual analysis of a global phenomena. *Online Journal of Rural Nursing and Health Care*, 21(1). https://doi.org/10.14574/ojrnhc.v21i1.676.
- DeGuzman, P. B., Bernacchi, V., Cupp, C. A., Dunn, B., Ghamandi, B., Hinton, I. D., Jameson, M. J., Lewandowski, D. L., & Sheffield, C. (2020). Beyond broadband: digital inclusion as a driver of inequities in access to rural cancer care. *Journal of cancer survivorship:*research and practice, 14(5), 643–652. https://doi.org/10.1007/s11764-020-00874-y
- Deshields, T. L., Heiland, M. F., Kracen, A. C., & Dua, P. (2016). Resilience in adults with cancer: development of a conceptual model. *Psycho-oncology*, *25*(1), 11–18. https://doi.org/10.1002/pon.3800
- Dooley, L. N., Slavich, G. M., Moreno, P. I., & Bower, J. E. (2017). Strength through adversity: Moderate lifetime stress exposure is associated with psychological resilience in breast cancer survivors. *Stress and health: journal of the International Society for the Investigation of Stress*, 33(5), 549–557. https://doi.org/10.1002/smi.2739
- Farmer, J., Bourke, L., Taylor, J., Marley, J. V., Reid, J., Bracksley, S., & Johnson, N. (2012).

  Culture and rural health. *The Australian journal of rural health*, 20(5), 243–247.

  <a href="https://doi.org/10.1111/j.1440-1584.2012.01304.x">https://doi.org/10.1111/j.1440-1584.2012.01304.x</a>
- LeBaron V. T. (2018). What Is the Rural Cultural Perspective?. *Oncology nursing* forum, 45(6), 683–685. https://doi.org/10.1188/18.ONF.683-685
- Rawl, S. M., Dickinson, S., Lee, J. L., Roberts, J. L., Teal, E., Baker, L. B., Kianersi, S., &

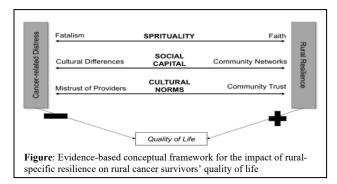
- Haggstrom, D. A. (2019). Racial and Socioeconomic Disparities in Cancer-Related Knowledge, Beliefs, and Behaviors in Indiana. *Cancer epidemiology, biomarkers & prevention: a publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology*, 28(3), 462–470. https://doi.org/10.1158/1055-9965.EPI-18-0795
- Reid-Arndt, S. A., & Cox, C. R. (2010). Does rurality affect quality of life following treatment for breast cancer?. *The Journal of rural health : official journal of the American Rural Health Association and the National Rural Health Care Association*, 26(4), 402–405. https://doi.org/10.1111/j.1748-0361.2010.00295.x
- Schootman, M., Homan, S., Weaver, K. E., Jeffe, D. B., & Yun, S. (2013). The health and welfare of rural and urban cancer survivors in Missouri. *Preventing chronic disease*, *10*, E152. https://doi.org/10.5888/pcd10.130052
- Weaver, K. E., Geiger, A. M., Lu, L., & Case, L. D. (2013). Rural-urban disparities in health status among US cancer survivors. *Cancer*, 119(5), 1050–1057. https://doi.org/10.1002/cncr.27840
- Zahnd, W., & Jenkins, W. D. (2018). Rural Women's Perceptions About Cancer Disparities and Contributing Factors: a Call to Communication. *Journal of cancer education: the official journal of the American Association for Cancer Education*, 33(4), 749–756. https://doi.org/10.1007/s13187-017-1196-5

# Chapter 2

# **Dissertation Proposal**

# **Specific Aims**

Nearly 20% of rural cancer survivors experience cancerrelated distress (CRD; the psychological, social, spiritual, or physical symptoms that impact survivors' quality of life) compared to ~13% of urban survivors. <sup>42,38</sup> CRD impacts multiple health outcomes for rural cancer survivors; CRD increases mortality risk, and decreases quality of life (QoL). <sup>68</sup> In fact, rural cancer survivors have identified a critical need for interventions that improve their QoL, and for those interventions to be both



geographically accessible and culturally-relevant.<sup>49</sup> For example, rural cancer survivors prefer to self-manage CRD using community-based support.<sup>73</sup> One way for nurses to support survivors' QoL through the self-management of CRD is to promote *resilience*, or the ability to make positive adaptations despite adversity, using community-based resources.<sup>13,64</sup> Cancer survivors with higher resilience have less CRD and improved QoL (see **Figure**).<sup>9,28,69</sup> However, resilience as experienced by rural survivors is poorly understood within the rural cultural and geographic contexts.<sup>70</sup> Therefore, there is little evidence to guide the development and implementation of interventions promoting resilience in rural cancer survivors.<sup>67,70</sup>

To begin guiding strategies for "how" and "where" to implement community-based interventions promoting resilience in rural cancer survivors, our team has developed an evidence-based conceptual framework for *rural resilience* (**Figure**). Our conceptual framework incorporates culturally-relevant and geographically accessible impacts of resilience on rural cancer QoL: faith, community networks and community trust increase resilience, while fatalism, cultural differences and mistrust of providers decrease resilience. The next steps are to identify community sources of resilience in rural cancer survivors guided by our conceptual model. Thus, the goals of this proposal are to 1) explore the cultural and geographic contexts of rural resilience, and 2) identify geospatial clusters of existing locations that promote rural resilience, in order to prioritize potential target sites for future community-based interventions for rural cancer survivors.

My long-term research goal is to develop and test interventions that target rural resilience in rural cancer survivors to improve QoL and decrease CRD. This proposal builds on preliminary work I've done with Dr. Zoellner (sponsor) and Dr. DeGuzman (co-sponsor), in which I've explored gaps in current survivorship care models through geospatial, qualitative and quantitative analysis. In the proposed formative research, I will use our conceptual model as a guide to explore the cultural and geographic context of rural resilience in cancer survivors living in rural Southwest Virginia using ethnography and geospatial analysis. The findings of this study will position me for future interventional research, and this proposal will serve as a foundation for my goal of becoming an independent nurse scientist. **The specific aims are:** 

<u>Aim #1:</u> Explore and describe individual and social facilitators and barriers to rural resilience in rural cancer survivors through the attributes of the conceptual model (faith, community networks, community trust, fatalism, cultural differences, mistrust of providers). *Conduct field* 

immersion, semi-structured interviews with rural cancer survivors and their primary family or community caregiver.

<u>Aim #2</u>: Identify and prioritize potential target sites (locations of faith, community networks, and community trust) for future community-based interventions to promote rural resilience. Conduct field immersion and semi-structured interviews to identify locations rural cancer survivors use to increase resilience. Perform geospatial cluster analysis to evaluate patterns of access points for rural resilience.

Key strengths of this proposal are my clinical and research experiences working with rural Virginia cancer survivors, and the University of Virginia Cancer Center's strong history of collaboration with the Southwest Virginia cancer community via the Southwest Virginia Community Advisory Board (CAB). Members of this CAB are committed to this proposal and will advise on every step of this proposal. All members of this interdisciplinary mentorship team are CAB members, have guided the development of this proposal, and are deeply committed to the applicant's training and success. The proposed research is highly responsive to the NINR's goal to "identify the basic mechanisms that influence successful self-management, in multiple conditions and settings, including the examination of mediators and moderators of self-management that impact adherence to treatment and sustainability or that impact interventions," and the concept of rural resilience in cancer survivors is both novel and relevant to nursing practice. Future directions of this study integrate well with NINR's focus on "patient-focused self-management programs that engage individuals and families." This formative research will serve as a strong foundation for a future program of research in rural resilience.

# **Significance**

Rural cancer survivors critically need interventions to improve their quality of life and reduce cancer-related distress. There are approximately 3 million cancer survivors living in rural US communities who experience greater cancer-related distress (CRD) and worse quality of life (QoL)<sup>53</sup> compared to urban survivors. <sup>42,43,44</sup> Rural cancer survivors also experience higher mortality rates, <sup>46,96</sup> poorer overall health, mental health, and post-treatment functioning. <sup>44,47</sup> Social determinants of health contributing to rural cancer disparities include: more comorbidities, higher rates of unemployment, and are less likely to have health insurance. <sup>42,46</sup> To address rural cancer disparities, rural cancer survivors have identified (QoL) as a priority research area. <sup>49</sup>

Interventions to improve quality of life in rural cancer survivors need to be geographically accessible. Rural cancer disparities, such as CRD and QoL, are attributed to the poor healthcare access of rural communities. 53,57 Rural cancer survivors experience poor access to health care due to local hospital closures, 71 provider shortages, 42 and long travel distances to care. 46 Due to poor healthcare access, rural cancer survivors are often unable to travel to their post-treatment follow up appointments, 36 and may not be able to communicate their health concerns with providers. 16 It is necessary to adapt interventions targeting quality of life in cancer survivors to be accessible for rural communities. 36 One way to make interventions

It's not easy here in [a rural town]... It takes me an hour to drive there. I have sister-in-law and a niece here on the farm, and we've had our chats [for support].

rural cancer survivor, female, 71yrs, participant in Dr. DeGuzman's study

improving QoL and CRD accessible is to implement them within existing community structures; community-based interventions have effectively reduced CRD.<sup>59</sup> However, locations for community-based interventions should be carefully considered, as many rural cancer survivors

experience isolation from their own communities due to lack of transportation and long drive times.<sup>37</sup>

# Effective interventions to improve quality of life in rural cancer survivors need to be culturally-relevant.

Geographic location and culture impact cancer beliefs and behaviors. <sup>20,137</sup> Interventions tailored

I wish [the nurse] could have covered spiritual care ...[spiritual interventions] are the things I'm doing to try and get better.

rural cancer survivor, male, 67yrs, participant in Dr. DeGuzman's study to meet an individuals' cultural context, such as telephonic cancer screening, are more effective at improving health outcomes. <sup>5,18,76,138</sup> Culturally-relevant interventions, such as faith-based nursing for cancer care, are accepted by rural residents. <sup>95</sup> However, many cancer interventions are not considered to be culturally-relevant by rural cancer survivors. <sup>42,62,92</sup> To be culturally-relevant, interventions should integrate rural survivors' cultural values, such as community networks, community trust, and faith. In our literature review, we found that rural

cancer survivors value strong community networks,<sup>52</sup> which may be challenging to maintain during cancer treatment.<sup>51</sup> Many rural survivors identify a major post-treatment goal of returning to their community setting and re-engaging with their community networks.<sup>51</sup> Rural cancer survivors report mistrusting providers,<sup>50,54</sup> or simply *preferring* to seek support from trusted community sources, such as family, peers, and spiritual leaders.<sup>73</sup> Spirituality is also critical to consider in intervention development for cancer survivors,<sup>39,21</sup> particularly in rural areas.<sup>94</sup> In rural communities, faith is associated with community, support, and identity, making spirituality an important value to consider in strategies and locations for interventions. <sup>52,54,56,60,62</sup> A comprehensive understanding of the rural cultural context is needed to develop interventions for survivors.<sup>30,67</sup>

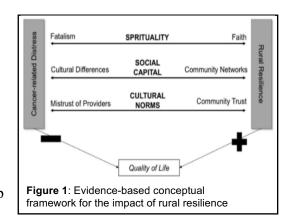
Interventions targeting resilience are ideal for improving quality of life and decreasing cancer-related distress while being culturally-relevant and geographically accessible. <sup>93</sup> Cancer survivors with higher levels of resilience experience increased QoL and decreased CRD. <sup>4,6,7,8,11,12,29</sup> Interventions targeting resilience in cancer survivors often incorporate family/community caregivers. <sup>1,2,3,15,17,32</sup> In fact, social support may be one of the strongest facilitators of resilience in cancer survivors. <sup>7,10,14,139</sup> Since rural cancer survivors often prefer to receive care from family and

community caregivers, <sup>73</sup> community-based interventions promoting resilience to increase QoL and decrease CRD may meet the unique cultural and geographic needs of rural cancer survivors. <sup>54</sup>

However, there are few interventions targeting resiliency in cancer survivors, and these may not address rural cultural and geographic context. <sup>89-91</sup> **Figure 1** contains an evidence-based conceptual model our team developed of rural resilience, in which we identified impacts of resilience on rural cancer survivors. In our literature review, we found that three main cultural dimensions of rural culture associated with increasing or decreasing resilience. The domain of social capital increases resilience through community networks and social interactions, <sup>75</sup> which motivate cancer survivors to make and sustain post-treatment health, <sup>55</sup> and may improve CRD and QoL. <sup>52,53,63</sup> In the domain of cultural norms, a strong sense of community trust <sup>54</sup> increases rural survivors' positive health perceptions. <sup>52</sup> Importantly, rural cancer survivor *chose* to seek social support from their community. <sup>56</sup> In the domain of spirituality, many rural cancer survivors identify faith as a source of meaning-making and strength when facing health challenges. <sup>52,54,56,60</sup> Attributes in these domains that decrease resilience are fatalism (spirituality), cultural differences (social capital), and mistrust of providers (cultural norms). These attributes may motivate poor

adherence to follow up care and poor self-management of CRD.<sup>50,58,62</sup> Further research is needed to contextualize the impacts of resilience in rural cancer survivors for intervention development.<sup>45,48</sup>

Innovation. Our study is highly innovative because we will research the existing community-based strengths that impact health of rural cancer survivors. Much of rural cancer survivorship literature focuses on healthcare access<sup>42,44,46,49</sup>, but we will research and disseminate a robust narrative of rural resilience by investigating both "how" and "where" to promote resilience in rural cancer survivors. Current interventions to improve CRD may not be effective because cancer care is not always culturally appropriate or accessible. By contrast, our study will explore how culture and location may support interventions. Our study will impact the field of rural survivorship care by guiding how supportive care services are designed for rural cancer survivors.



# **Approach and Analysis**

**Research Design.** The overall study design is a combination of ethnography and descriptive geospatial analysis, underpinned by the principles of community-based participatory research (CBPR). This design is highly appropriate to successfully address health disparities in rural communities. 15,87,95 Ethnographic methodology will provide a robust understanding of the social and cultural context of rural resilience in cancer survivors, 103 while spatial analysis enhances our understanding of the relationship that the environment has with those contexts. 136,137 The combination of ethnography and geospatial analysis, underpinned by CBPR, promotes a holistic, community-based approach to patient outcomes highly relevant to public health nursing science. 136 The strengths of this approach include 1) contextual knowledge pertinent to developing maintainable interventions based on existing community strengths, 95 and 2) inclusion of family and community caregivers, which is necessary since resilience is highly associated with social support. 19,24,26,32,34 Another significant strength is our use of geospatial analysis, which permits the visualization of multidimensional data (behavioral, social, and environmental) to guide future research.<sup>25</sup> In nursing science, geospatial analysis can identify community locations to implement feasible, acceptable and cost-effective interventions. 122 Underpinning Principles of CBPR. Given the tenuous history rural communities have with the perpetuation of stereotypes,<sup>54</sup> incorporating the principles of CBPR to underpin our study design is ethically necessary. 88,95,101 Our incorporation of CBPR principles (community resources, involvement, and capacity)<sup>99,117,142</sup> is centered around the regional community advisory board, which provides the infrastructure for community resources, involvement, and capacity. <sup>100,127</sup> Dr. Zoellner is an expert in CBPR, and will oversee the implementation of CBPR principles. **Description of the population.** The selected target population of this proposal is rural, posttreatment cancer survivors in Southwest Virginia, and their family or community caregivers. Residents of Southwest Virginia report some of the poorest health behaviors in the country. 143 Rural cancer survivors in Southwest Virginia face numerous barriers related to the social determinants of health, such as poverty, unemployment, chronic disease, opioid abuse, housing

and food insecurity, <sup>126</sup> unemployment, <sup>123</sup> racism, <sup>124</sup> and high risk of accidents. <sup>125</sup> Additionally, there is low prevalence of health insurance or health providers. <sup>115,118</sup>

Social determinants of health impacting the population. Rural cancer survivors in Southwest Virginia face numerous barriers related to the social determinants of health, such as poverty, unemployment, chronic disease, and low prevalence of health insurance or health providers. 115,137 Key social determinants of health impacting this population include access to care, lack of public transportation, and poverty, which have all contributed to poor health outcomes for SWVA communities. 114 Additionally, housing insecurity, unemployment, 123 as well as food insecurity, 126 racism, 124 and high risk of accidents impact health outcomes for rural cancer survivors. 125 Notably, Southwest Virginia also reports the highest regional mortality rates due to opioid abuse, which is considered a challenging issue due to cultural norms. 118 Understanding the relation of social determinants of health in this population is critical because of the dynamic interaction between individuals, communities, environments, and cultural norms. Researchers of diabetes outcomes have been able to develop effective culturally tailored interventions through knowledge of the social determinants of health. 122 We believe we can mirror their success in the development of culturally tailored interventions to improve psychosocial outcomes by promoting resilience in rural cancer survivors.

**Setting**. Southwest Virginia encompasses a large region of rural Central Appalachia along the Virginia-Tennessee and Virginia-West Virginia border. The region is hazardous, sparsely populated and geographically isolated, with poor healthcare access and lack of public transportation. This region was chosen because the population is highly vulnerable to poor health outcomes, and because of my mentors' existing collaborative research relationships in the region. Its, 116, 118, 119

**Southwest Virginia Community Advisory Board (SWVA CAB)**. Partnership with the SWVA CAB is integral to the achievement of this proposal's aims. The SWVA CAB was established in 2013, and consists of academic partners from UVA and Virginia Tech, as well as key stakeholders from the Health District representatives, <sup>129</sup> Southwest Virginia Community Health Systems, local religious community leaders, and nurse educators from Southwest Virginia Community Colleges. The SWVA CAB has experience in participant recruitment, intervention development and implementation. <sup>119,131,128</sup> A subgroup of SWVA CAB members has been formed to guide research for rural cancer survivors, led by Dr. Porter.

**Preliminary Research and Training.** This proposal builds on research and training I've completed the past two years with my dissertation chair, Dr. DeGuzman and committee members. My preliminary work for this proposal has occurred through four capacities: 1) building trust and rapport with key community stakeholders through participation with the Southwest Virginia Community Advisory Board, guided by Drs. Zoellner and Porter 2) experience in both in-person and virtual field work and interviews with rural cancer survivors, guided by Drs. DeGuzman and LeBaron 3) experience in thematic analysis with Dr. DeGuzman and Dr. LeBaron, and 4) experience in geospatial analysis with Dr. DeGuzman.

<u>Aim #1:</u> Explore and describe individual and social facilitators and barriers to rural resilience in rural cancer survivors through the attributes of the conceptual model (faith, community networks, community trust, fatalism, cultural differences, mistrust of providers).

Drs. Zoellner, DeGuzman, and Porter will oversee participant recruitment. Drs. DeGuzman and Porter from their respective studies, and Drs. Zoellner and Porter through community

gatekeepers in the SWVA CAB. Drs. Zoellner and Porter will oversee the process of gaining entrée to the community, and Dr. LeBaron will guide data collection and analysis. **Sample.** We will recruit 20 cancer survivors and their primary caregivers for a total of n=40participants from rural Southwest Virginia to participate in semi-structured interviews. 40 participants is our estimated sample size to reach data saturation (the point at which we see repeated themes, and no new themes). 97,98,102 However, our research design is flexible based on emerging data, and we plan to increase our sample to 25-30 rural survivors and caregivers if needed to achieve data saturation.<sup>97</sup> Rural cancer survivors' eligibility criteria includes: completion of treatment from the participant's first cancer diagnosis, being within 5 years of cancer treatment (this time frame was chosen to allow participants to reflect on the transition to the extended survivorship phases), <sup>27,120</sup> and residency of an American Community Survey rural defined zip code in Southwest Virginia. <sup>121</sup> Eligibility criteria for principle caregivers includes: any family member, friend, or partner who the rural cancer survivor identifies are their main source of support and assistance. 1,2,65 We will use purposive sampling based on eligibility criteria, snowball sampling with enrolled participants, <sup>66</sup> and will sample iteratively as themes emerge from the data.<sup>97</sup> For observational data collection, we anticipate recruiting an additional 40-60 participants. 97 These participants will be people who influence rural resilience through their engagement with rural cancer survivors and their caregivers. Eligibility criteria is interaction with a rural cancer survivor and/or their family or community caregiver that influences spirituality, cultural norms or social support. We anticipate this will include family, friends, healthcare providers, community members, and spiritual leaders.

Recruitment. I am well positioned to recruit 20 rural cancer survivors and 20 family or community caregivers for participant interviews, and to also recruit a 40-60 participants for observational data collection. Recruitment will occur through 1) the mentorship team's ongoing and recently completed research, and 2) the regional Relay for Life and Clinch Valley Cancer Survivorship Dinner, which are community events for cancer survivors at which Dr. Porter and a key gatekeeper of the SWVA CAB, 81 Ms. Betsy Grossman, will facilitate necessary introductions for me. Ms. Grossman is a long-time resident of Southwest Virginia, a cancer survivor, and worked as the Outreach/Clinical Trials Navigator for the UVA Cancer Center. Ms. Grossman will introduce me to key members from the region's Relay for Life, an annual event that many rural cancer survivors and their caregivers participate in. Dr. Porter is familiar with organizers and attendees of the annual Cancer Survivorship Dinner with Clinch Valley, a local health facility. Dr. Porter will introduce me to members, organizers and attendees of the annual Clinch Valley Survivorship Dinner. The recruitment strategies and estimated number of participants to be recruited from each strategy are shown in Table 4.

Table 1. Recruitment Plan						
<b>Recruitment from Mento</b>	r's Research	Recruitment from Community Events				
Dr. DeGuzman's ongoing	Dr. Porter's completed	Gatekeeper: Betsy	Gatekeeper: Dr. Porter			
telemedicine study with	study with rural cancer	Grossman	Event: Clinch Valley			
rural cancer survivors	survivors in Southwest	<b>Event:</b> Relay for Life	Cancer Survivorship			
(anticipated <i>n</i> =6	Virginia (anticipated <i>n</i> =9	(anticipated $n=5-8$	Dinner (anticipated <i>n</i> =5			
survivors, <i>n</i> = 6	survivors, <i>n</i> =9	survivors, <i>n</i> =caregivers)	survivors, <i>n</i> =caregivers)			
caregivers.	caregivers)	,				

For observational data, recruitment will occur as rural cancer survivors and their family or community caregivers engage in activities of daily living. In accordance with the UVA Institutional Review Board's policy, participants who provide only observational data are not required to consent, although a verbal consent will be obtained whenever possible. We anticipate our recruitment strategies will yield successful enrollment of 20 rural cancer survivors, 20 caregivers of rural cancer survivors, and 40-60 family members, friends, healthcare providers and community members who interact with them during day-to-day activities. However, we have planned additional recruitment strategies if needed, which include outreach to providers of the Cancer Action Coalition of Virginia, a statewide organization that both the PI and Dr. DeGuzman are members of. Additionally, Dr. Zoellner and Dr. Porter have an extensive history working with the Blue Ridge Cancer Center, which we will reach out to for additional participant recruitment if needed.

**Retention.** We will gather both phone and email contact information from all participants, and the PI will schedule participant interviews once participants have been screened for eligibility, enrolled, and consented. Once participants enroll in the study, the initial interview is scheduled and information related to the study procedures are provided. The initial interview will be scheduled for within 48 hours of participant consent. In the event the participant is not able to schedule an interview within 2-3 days of consenting, we have chosen three main retention strategies that have been successful with studies in this region before based on Drs. Zoellner's and Porter's research experience: 1) participants will receive a reminder post-card one week prior to their interview, and reminder phone call 1-2 days before their interview, 2) if participants cannot be contacted after four telephone/email efforts, and for telephone numbers that are disconnected, a letter will be mailed encouraging participation. The participants of the participants are disconnected, a letter will be mailed encouraging participation.

Gaining Entrée and Building Trust with Community Members. Data collection will occur primarily through participant observations and interactive semi-structured interviews. 103 Therefore, gaining entrée and building trust with the community is a critical to the proposal's success. 110 With my mentorship team, I have developed a three-pronged approach to gaining entrée and building trust with participants. First, I have existing rapport with rural cancer survivors from working as the research assistant for Dr. DeGuzman's study the past two years. Second, the SWVA CAB has key community stakeholders and gatekeepers, such as Betsy Grossman. Ms. Grossman and Dr. Porter will introduce me and my research to community members. Finally, I will gain entrée and build trust through prolonged field immersion. I will live and work in Southwest Virginia-specifically Christiansburg, where Drs. Zoellner and Porter are located and have offices-for 12 months. This period of prolonged engagement was chosen so that the first two to three months can be spent fully integrating into the community and building rapport with participants. 85 In the event that COVID-19 limits my ability to fully immerse in the community, the SWVA CAB community gatekeepers such as Ms. Grossman will facilitate the necessary introductions for me to gain entrée and build trust via virtual platforms, such as the Southwest Virginia Support Group for Cancer Survivors.

**Data Collection.** I will collect data over the course of 12 months of intensive field immersion from June 2021 to June 2022, during which I will live in rural Southwest Virginia. <sup>110</sup> I will relocate to Christiansburg, a rural town in Southwest Virginia which houses the Cancer Without Walls project, along with Drs. Zoellner's and Porter's offices. Participant recruitment, data collection and data analysis will occur concurrently and iteratively in this flexible study design to achieve data saturation. <sup>104</sup> As is consistent with the principles of ethnography, data will be

collected through field work, semi-structured interviews, and relevant documents or artifacts. 78,107,108,110

Participant observations. Field work (the documentation of social environments, interactions, and behaviors) will be used to collect observational data, which will be recorded daily as jottings, and then expanded into field notes with rich, thick description of the community setting, interactions, and behaviors. 81,131 Based on our evidence-based conceptual model and my preliminary research, I expect that participant observations will occur in faith-based institutions, such as local churches, outdoor walking groups, local parks and restaurants, and participant homes. However, I am also prepared to collect virtual participant observations if the impact of COVID-19 makes in-person data collection limited, or even impossible. Based on my conversations with key community leaders, the cancer survivor support group in Southwest Virginia has active online forum and social media groups. Virtual ethnography is not ideal, but many social interactions are now mediated by the virtual environment. <sup>105</sup> Virtual environments and interactions can be considered both a culture and cultural artifact, making virtual ethnographic techniques integral to understanding rural resilience within the rural context in a post-pandemic society. 105 We anticipated virtual environments to include: web-based interviews, local cancer support groups through social media, virtual meetings of support groups from the local cancer clinics, and blog posts. If virtual data collection is necessary, I have two years of experience collecting participant observations via video-conferencing through Dr. DeGuzman's research.

Semi-structured interviews. Semi-structured interviews will be audio-recorded and are anticipated to last approximately 60 minutes. <sup>104,132</sup>. There will be three types of interview questions that participants engage in: 1) oral history, which will be used to understand the participant's unique context and experience with rural resilience, 2) personal narratives, which will be used for participants to share stories of how attributes of our conceptual model (faith, fatalism, community networks, cultural differences, community trust and provider mistrust) have

impacted rural resilience, and 3) topical interviews, which will be used to identify optimal strategies for promoting rural resilience.<sup>83</sup> Since resilience is highly impacted by social qualities and social support, many interview questions will revolve around participants' perceptions of social support. 31,34-35 Thus, if interviews occur with both the rural cancer survivor and their caregiver, there is a risk of introducing bias through "desirability pressures," in which participants give the answer they believe is culturally and socially acceptable. 33 To minimize this risk, Dr. LeBaron and I have developed the following plan: interviews will occur individually with rural cancer survivors, and individually with their family/community caregivers, whenever possible. Interview questions will be open-ended to elicit experiences of rural resilience, 83,85 and will be adapted iteratively based on emerging themes. 131 Table 5 depicts potential interview questions. Participants may be contacted for additional interviews based on the emerging themes.<sup>85</sup> In the event I am not able to interview participants in-person due to COVID-19, interviews will occur over a HIPPA-compliant videoconferencing system, WebEx. I

# Table 2. Sample interview questions for Aim 1.

Can you tell me about a time when your community networks helped you feel supported after (your loved one's) cancer treatment?

Please tell me about the role, if any, that spirituality has in your (loved one's) post-treatment care.

What, or who, do you think has helped you (your loved one) to adapt to being a cancer survivor?

have two years of experience with virtual semi-structured interviews with rural cancer survivors.

If participants don't have a video-capable device, we have an ipad with pre-loaded data to mail to them for the interview.

Documents or artifacts. Data collection will occur through systematic review of local newspapers, policies of agencies impacting rural resilience (such as local clinics, churches, and support groups), and photographs of the places rural cancer survivors travel to. <sup>95</sup> Data from documents and artifacts will provide robust information of the socio-political contexts impacting rural resilience. <sup>95</sup>

Data Analysis. Data analysis will occur in the systematic process of thematic analysis, and will be guided by our conceptual model (Figure 1), with the goal of reaching data saturation. <sup>136</sup> To reach data saturation, I will be concurrently collecting and analyzing data, will have prolonged field immersion, and will continue iterative analysis until repeated themes emerge from participant data.<sup>97</sup> The process of analysis is as follows: first, field notes will be expanded on for the purpose of thick, rich description enabling interpretation of social meaning and context to participants' actions, organized chronologically, <sup>106,107,11</sup> then be analyzed for patterns of rural resilience in rural cancer survivors, and the interaction of rural resilience with the sociocultural context. Key observations will be categorized as expected or unexpected observations, and coded. 136 Recorded interviews will be transcribed and cleaned. 132 Formal interview transcription will be coded using NVIVO software, using two coding strategies, 1) a systematic theoretical coding schema based on the our conceptual model (Figure 1) of rural resiliency, and 2) open coding. 84,135 The unit of analysis will be phrases or sentences to determine meaning and context.<sup>108</sup> Reflexive journaling<sup>79,80,82</sup> and analytic memos will be used to further contextualize findings, and an audit trail will ensure rigor. <sup>108</sup> Thematic analysis will be used to extract key themes from interview and observational data, <sup>133,134</sup> which will be further contextualized and defined in terms of their relationships to each other. Preliminary findings will be triangulated by data from observations, interviews, and artifacts, <sup>78</sup> and discussed with the mentorship team for the purpose of peer debriefing. 110 Then, findings will be presented to the SWVA CAB to contextualize observational and interview data, member-checking, <sup>110</sup> and dissemination of findings to the community. 109,111

**Expected Outcomes.** I expect to obtain over 500 hours of field observations, and a minimum of 20 interviews with rural cancer survivors, and 20 interviews with the primary family/community caregiver of rural cancer survivors. These data will be interpreted to illuminate how rural cancer survivors' experiences regarding resilience are generated by their social structures. We anticipate providing a comprehensive emic perspective on resilience in rural cancer survivors that will guide strategies for future intervention development.

<u>Aim #2:</u> Identify and prioritize potential target sites (locations of faith, community networks, and community trust) for future community-based interventions to promote rural resilience.

The mentorship team will maintain the same roles as with Aim 1, except that Dr. DeGuzman will oversee data management and analysis. The sample, recruitment, retention, eligibility, and data collection are the same for Aim 2 as for Aim 1, with the following exceptions:

**Sample.** Only rural cancer survivors (n=20) and their family or community caregivers (n=20) will be recruited.

**Data collection.** Data collection for Aim 2 will occur concurrently with data collection for Aim 1.

*Participant observations*. I will engage in field work to specifically document participants' social environments. <sup>112</sup> I will collect participant observations regarding places participants travel to for increased resilience, descriptions of those locations, and the method of travel. The address and description of locations rural cancer survivors travel to for increased resilience will be recorded daily as jottings, and then expanded into field notes. <sup>81,131</sup> In the event COVID-19 prohibits inperson field work, I will use virtual ethnography to note social media platforms survivors use to seek faith, community networks or community trust. <sup>105</sup>

Semi-structured interviews. Interview structure will be the same as Aim 1. Rural survivors and

their caregivers will be interviewed separately about locations they travel to for faith, community networks, and community trust. Topical interview questions will be guided by our conceptual model of rural resilience to identify specific places rural cancer survivors go to for increased resilience. Table 6 depicts potential interview questions.

Geocoding locations of faith, community networks, and community trust. I will extract the addresses of places rural cancer survivors travel to for increased resilience from participant observations and from semi-

# Table 3. Sample interview questions for Aim 2.

Can you tell me about places you and your loved one go to in order to feel faith?

Tell me about a time you felt community trust.

If you need to connect with your community, where is the best place for you to go?

structured interviews. Geocoding, which is the process of identifying the exact spatial location of an address by the location's latitude and longitude coordinates, will be used for descriptive mapping. To identify geocodes, we will first use the U.S. Census Geocoder. If I am unable to successfully geocode a location with the U.S. Census Geocoder, I will use Google Maps to determine the location's latitude and longitude coordinates. I expect some "locations" that support rural resilience to be virtual platforms, such as online support groups and social media. To capture virtual sources of rural resilience, I will geocode the location that rural cancer survivors use to access virtual platforms, with the assumption that this location may be a place other than home, such as a local library, due to limited broadband in rural Virginia.

Geospatial Analysis. Descriptive maps of locations that rural cancer survivors travel to for faith, community networks and community support will be produced in ArcGIS Pro, an online geospatial software system I have access to through UVA. Base maps of the environmental characteristics (roads, parks, railroads) of Southwest Virginia are available through the UVA Spatial Tech at the Scholar's Lab. Analysis of spatial clustering will be used to determine potential target sites of future interventions that promote resilience in rural cancer survivors. Density-based clustering has been successfully used to identify target sites for community-based interventions. 41,136.137 I will use density-based clustering to perform spatial cluster analysis in ArcGIS Pro. Density-based clustering was chosen to determine where concentrated clusters of locations that support rural resilience exist in Southwest Virginia. 40,41 Once clusters of locations rural cancer survivors travel to for increased resilience are identified, I will calculate the distribution of distance (driving time and distance) between all locations within each cluster to prioritize locations for future interventions. Using ArcGIS Pro, I will be able to measure driving time and distance while accounting for typical traffic patterns and speed limits. This geospatial analysis will provide a comprehensive understanding of target locations to implement interventions that increase rural resilience in rural cancer survivors.

**Expected Outcomes.** We expect to identify and prioritize specific locations in Southwest Virginia with a high number of existing sources of faith, community networks, and community

trust. These locations will serve are potential target areas for future intervention implementation. We also expect to report on using geospatial clustering methods to identify target locations for intervention implementation in other rural communities. We expect that we will publish three manuscripts based on data from aims 1 and 2 of this study.

**Table 4. Plan for Manuscript Dissemination** 

Anticipated	Anticipated Manuscript Title	Anticipated Journal for
Year of		Submission
Submission		
2023	Target Locations for Interventions in Rural	Journal of Public Health
	Communities to Reduce Cancer-Related	Nursing
	Distress	
2023	Sources of Rural Resilience in the Rural	Journal of Rural Health
	Cultural and Geographic Context	
2024	Culturally-Tailored Strategies for How and	Journal of Cancer Survivorship
	Where to Promote Rural Resilience in	
	Cancer Survivors	

Potential Limitations and Strategies to Overcome. The target population may be challenging to recruit based on geographic location and potential mistrust of clinicians/researchers. 46,53,74 I am well positioned to overcome recruitment challenges with this population because 1) I already have established rapport with several potential participants from Dr. DeGuzman's study, 2) I have permission to recruit from 2 studies that have successfully recruited this population, and 3) my, and my mentors' membership with the SWVA CAB enables me to network with key community gatekeepers. A second anticipated limitation is in-person field immersion due to COVID-19. However, contemporary ethnography is no longer limited by community borders, especially in our post-pandemic society. 104 Virtual ethnographic methods are adaptable are appropriate for exploring relations and interactions. <sup>105</sup> I have received training in virtual ethnographic techniques in a webinar "Virtual Fieldwork Across Online Spaces", am experienced in virtual observational and interview data collection from my work with Dr. DeGuzman's telemedicine study. Specific to Aim 2, there is the potential of problems geocoding rural locations, particularly the places rural survivors use to connect to virtual platforms. Dr. DeGuzman is well-versed in geospatial analysis and software, and I will have access to two GIScertified experts available for analysis and software support from the University of Virginia Spatial Tech team.

**Feasibility.** Target recruitment and enrollment for Aims 1 and 2 are feasible due to the available sampling pool from Drs. Porter and DeGuzman's research. The robust training plan in ethnography, geospatial analysis, and public health make it feasible to complete the aims of this study within the proposed timeline.

**Study Timeline.** The timeline for this proposal is 24 months (May 2021-May 2023) including training in ethnography and geospatial analysis, implementation of study procedures and dissemination of results.

Table 5. Timeline for proposed study	Y 1 (2021)		Y 2 (	2022)		
Aims/Tasks	Q3	Q4	Q1	Q2	Q3	Q4
Complete training coursework						
Complete Institutional Review Board protocol						
Participant Recruitment						
Gaining entrée with the community						
Data Collection						
Data Analysis						
Participant Recruitment						
Data Collection						
Data Analysis						
SWVA CAB member checking						
Dissemination to SWVA CAB						
Dissemination to scholarly community						
Postdoctoral applications and interviews						
Manuscript writing						
F32 postdoctoral grant preparation						

# **Chapter 2 References**

### Reference List

- [1]. Li Y, Wang K, Yin Y, Li Y, Li S. Relationships between family resilience, breast cancer survivors' individual resilience, and caregiver burden: a cross-sectional study. *International Journal of Nursing Studies*. 2018;88:79-84. doi: https://doi.org/10.1016/j.ijnurstu.2018.08.011.
- [2]. Liu Y, Li Y, Chen L, Li Y, Qu W, Yu L. Relationships between family resilience and posttraumatic growth in breast cancer survivors and caregiver burden. *Psychooncology*. 2018; 27(4):1284-1290. doi: 10.1002/pon.4668.
- [3]. Li Y, Qiao Y, Luan X, Li S, Wang K. Family resilience and psychological well-being among Chinese breast cancer survivors and their caregivers. *European Journal of Cancer Care*. 2019; e12984. doi: https://doi.org/10.1111/ecc.12984.
- [4]. Harms CA, Cohen L, Pooley JA, Chambers SK, Galvao DA, Newton RU. Quality of life and psychological distress in cancer survivors: the role of psycho-social resources for resilience. *Psychooncology*. 2019;28(2):271-277. doi: 10.1002/pon.4934.
- [5]. O'Brien I, Signal L, Sarfati D. Wide-ranging impacts reported by NZ cancer survivors: is supporting cancer survivor resilience a health sector role? *Support Care Cancer*. 2018:26: 1207–1213. doi: https://doi.org/10.1007/s00520-017-3943-x.
- [6]. Plitzko L, Mehnert-Theuerkauf A, Gotze H. Resilience in long-term cancer survivors-associations with psychological distress and sociodemographic characteristics. *Psychootherapie*. 2019;17. doi: 10.1055/a-0927-6782.
- [7]. Seiler A, Jenewein J. Resilience in cancer patients. *Front Psychiatry*. 2019;10:208. doi:10.3389/fpsyt.2019.00208.
- [8]. Zahid N, Khalid W, Ahmad K, et al. Resilience and quality of life (QoL) of head and neck cancer and brain tumour survivors in Pakistan: an analytical cross-sectional study protocol. *BMJ Open.* 2019;9(9):e029084. doi:10.1136/bmjopen-2019-029084.
- [9]. Gallagher MW, Long LJ, Richardson A, D'Souza JM. Resilience and coping in cancer survivors: the unique effects of optimism and mastery. *Cognit Ther Res.* 2019;43(1):32–44. doi:10.1007/s10608-018-9975-9.
- [10]. Lee JH, Kim HY. Symptom distress and coping in young Korean breast cancer survivors: the mediating effects of social support and resilience. *J Korean Acad Nurs*. 2018;48(2):241-253. https://doi.org/10.4040/jkan.2018.48.2.241.
- [11]. Oliva A, Garcia-Cebrian JM, Calatayud EF, Serrano-Garcia I, Herraiz MA, Coronada PJ. A comparison of quality of life and resilience in menopausal women with and without a history of gynaecological cancer. *Maturitas*. 2019;120:35-39. Doi: 10.1016/j.maturitas.2018.11.012.

- [12]. Maatouk I, He S, Becker N, et al. Association of resilience with health-related quality of life and depression in multiple myeloma and its precursors: results of a German cross-sectional study. *BMJ Open*. 2018;8(7):e021376. Published 2018 Jul 30. Doi:10.1136/bmjopen-2017-021376.
- [13]. Coughlin SS, Yoo W, Whitehead MS, Smith SA. Advancing breast cancer survivorship among African-American women. *Breast Cancer Res Treat*. 2015;153(2):253–261. doi:10.1007/s10549-015-3548-3.
- [14]. Bazzi AR, Clark MA, Winter MR, Ozonoff A, Boehmer U. Resilience among breast cancer survivors of different sexual orientations. *LGBT Health*. 2018;5(5):295–302. doi:10.1089/lgbt.2018.0019.
- [15]. Moen EL, Kapadia NS, O'Malley AJ, Onega T. Evaluating breast cancer care coordination at a rural national cancer institute comprehensive cancer center using network analysis and geospatial methods. *Cancer Epidemiol Biomarkers Prev.* 2019;28(3):455-461. doi:10.1158/1055-9965.EPI-18-0771.
- [16]. Quillin JM, Tracy K, Ancker JS, et al. Health care system approaches for cancer patient communication. *J Health Commun*. 2009;14 Suppl 1(Suppl 1):85-94. doi:10.1080/10810730902806810.
- [17]. Lim JW, Shon EJ, Paek M, Daly B. The dyadic effects of coping and resilience on psychological distress for cancer survivor couples. *Support Care Cancer*. 2014;22(12):3209–3217. doi:10.1007/s00520-014-2334-9.
- [18]. Rawl SM, Christy SM, Monahan PO, et al. Tailored telephone counseling increases colorectal cancer screening. *Health Educ Res.* 2015;30(4):622-637. doi:10.1093/her/cyv021.
- [19]. Lillie, H.M., Venetis, M.K., Chernichky-Karcher, S.M. "He would never let me just give up": communicatively constructing dyadic resilience in the experience of breast cancer. *Health Communication*. 2018; 33(12):1516-1524. doi: 10.1080/10410236.2017.1372049.
- [20]. Rawl SM, Dickinson S, Lee JL, et al. Racial and socioeconomic disparities in cancer-related knowledge, beliefs, and behaviors in Indiana. *Cancer Epidemiol Biomarkers Prev.* 2019;28(3):462-470. doi:10.1158/1055-9965.EPI-18-0795.
- [21]. Ellington L, Billitteri J, Reblin M, Clayton MF. Spiritual care communication in cancer patients. *Semin Oncol Nurs*. 2017;33(5):517-525. doi:10.1016/j.soncn.2017.09.002.
- [22]. Mosher CE, Winger JG, Given BA, Helft PR, O'Neil BH. Mental health outcomes during colorectal cancer survivorship: a review of the literature. *Psychooncology*. 2016;25(11):1261–1270. doi:10.1002/pon.3954.

- [23]. The Demographics Research Group. Virginia's regions. https://demographics.coopercenter.org/sites/demographics/files/RegionalProfiles\_28July2014\_0. pdf. Published 2014. Accessed July 7, 2020.
- [24]. Padilla-Ruiz, M., Ruiz-Román, C., Pérez-Ruiz, E. *et al.* Clinical and sociodemographic factors that may influence the resilience of women surviving breast cancer: cross-sectional study. *Support Care Cancer* 27, 1279–1286 (2019). https://doi.org/10.1007/s00520-018-4612-4.
- [25]. Docherty SL, Vorderstrasse A, Brandon D, Johnson C. Visualization of multidimensional data in nursing science. *West J Nurs Res.* 2017;39(1):112-126. doi:10.1177/0193945916672448.
- [26]. Coughlin, S.S. Surviving cancer or other serious illness: a review of individual and community resources. *Cancer: a cancer journal for clinicians*. 2008;58(1). doi: https://doi.org/10.3322/CA.2007.0001.
- [27]. Taylor MF, Pooley JA. Sarcoma/giant-cell tumor survivors' perspectives on their psychological journey. J *Psychosoc Oncol*. 2018; 36(6):681-699. doi: 10.1080/07347332.2018.1498425.
- [28]. Campo RA, Wu LM, Austin J, Valdimarsdottir H, Rini C. Personal resilience resources predict post-stem cell transplant cancer survivors' psychological outcomes through reductions in depressive symptoms and meaning-making. *J Psychosoc Oncol*. 2017;35(6):666–687. doi:10.1080/07347332.2017.1342306.
- [29]. Dooley LN, Slavich GM, Moreno PI, Bower JE. Strength through adversity: Moderate lifetime stress exposure is associated with psychological resilience in breast cancer survivors. *Stress Health*. 2017;33(5):549–557. doi:10.1002/smi.2739.
- [30]. Fuller-Thomson, E., & West, K. Flourishing despite a cancer diagnosis: factors associated with complete mental health in a nationally-representative sample of cancer patients aged 50 years and older. *Aging & Mental Health*. 2019;23(9): 1263-1274. doi: https://doi.org/10.1080/13607863.2018.1481926.
- [31]. Doege D, Thong M, Koch-Gallenkamp L. et al. The role of psychosocial resources for long-term breast, colorectal, and prostate cancer survivors: prevalence and associations with health-related quality of life. *Support Care Cancer*. 2019;27: 275–286. doi: https://doi.org/10.1007/s00520-018-4317-8.
- [32]. Hodgkinson K, Butow P, Hunt GE et al. Life after cancer: couples' and partners' psychological adjustment and supportive care needs. *Support Care Cancer*. 2007;15:405–415. doi: https://doi.org/10.1007/s00520-006-0148-0.
- [33]. Morgan DL. Essentials of Dyadic Interviewing. New York: Routledge; 2016.
- [34]. Roland KB, Rodriquez JL, Patterson JR, Trivers KF. A literature review of the social and psychological needs of ovarian cancer survivors. *Pyschooncology*. 2013;22(11):2408-2018. doi: 10.1002/pon.3322.

- [35]. Stewart DE, Wong F, Melancon CH, Cheung AM. "What doesn't kill you makes you stronger": an ovarian cancer survivor survey. Gynecol Oncol. 2001 Dec; 83(3):537-542.
- [36]. Schootman M, Homan S, Weaver KE, Jeffe DB, Yun S. The health and welfare of rural and urban cancer survivors in Missouri. Prev Chronic Dis 2013;10:130052. doi: http://dx.doi.org/10.5888/pcd10.130052.
- [37]. Mohatt NV. Prejudice, stigma, privilege, and oppression. Switzerland: Springer Nature; 2020.
- [38]. National Comprehensive Cancer Network. NCCN guidelines version 2.2018 distress management. https://oncolife.com.ua/doc/nccn/Distress\_Management.pdf. Published 2018. Accessed May 23, 2020.
- [39]. Bulkley J, McMullen CK, Hornbrook MC, et al. Spiritual well-being in long-term colorectal cancer survivors with ostomies. *Psychooncology*. 2013;22(11):2513–2521. doi:10.1002/pon.3318.
- [40]. National cancer institute. *Age and cancer risk*. https://www.cancer.gov/about-cancer/causes-prevention/risk/age. Published 2015. Accessed June 2, 2020.
- [41]. Dworkis DA, Weiner SG, Liao VT, Rabickow D, Goldberg SA. Geospatial clustering of opioid-related emergency medical services runs for public deployment of naloxone. *West J Emerg Med.* 2018;19(4):641-648. doi:10.5811/westjem.2018.4.37054.
- [42]. Weaver KE, Geiger AM, Lu L, Case LD. Rural-urban disparities in health status among US cancer survivors. *Cancer*. 2013;119(5):1050–1057. doi:10.1002/cncr.27840.
- [43]. Burris JL, Andrykowski M. Disparities in mental health between rural and nonrural cancer survivors: a preliminary study. *Psychooncology*. 2010;19(6):637–645. doi:10.1002/pon.1600.
- [44]. Butow PN, Phillips F, Schweder J. et al. Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: a systematic review. *Support Care Cancer*. 2012;20:1–22. doi: https://doi.org/10.1007/s00520-011-1270-1.
- [45]. Andrykowski MA, Lykins E, Floyd A. Psychological health in cancer survivors. *Semin Oncol Nurs*. 2008;24(3):193–201. doi:10.1016/j.soncn.2008.05.007.
- [46]. DeGuzman, P, Colliton, K, Nail, CJ, & Keim-Malpass, J. Survivorship care plans: rural, low-income breast cancer survivor perspectives. *Clinical Journal of Oncology Nursing*. 2017; 21(6), 692-698. doi: 10.1188/17.CJON.692-698.
- [47]. Bazzell, JL, Spurlock, A, & McBride, M. Matching the unmet needs of cancer survivors to resources using a shared care model. *Journal of Cancer Education*. 2015; 30(2), 312-318. doi: 10.1007/s13187-014-0708-9.

- [48]. Fuschsia, HA, Smillie, K, Turnbull, K, Zirul, C, Munroe, D, Ward, A, Tobin, P, Kazanjian, A, Olson, R. Access to medical and supportive care for rural and remote cancer survivors in northern British Columbia. *Journal of Rural Health*. 2014; 30(3), 311-321. doi: 0.1111/jrh.12064.
- [49]. Chen L, Payne JB, Dance KV, Imbody CB, Ho CD, Ayers AA, Flowers CR. Priorities for rural survivors: a qualitative study. *Clinical lymphoma, myeloma & leukemia*. 2019. doi: 10.1016/j.clml.2019.09.599.
- [50]. Livaudais JC, Thompson B, Godina R, Islas I, Ibarra G, Coronado GD. A qualitative investigation of cancer survivorship experiences among rural Hispanics. *Journal of psychosocial oncology*. 2010; 28(4):361–380. doi:10.1080/07347332.2010.488146
- [51]. Walker R, Szanton SL, Wenzel J. Working toward normalcy post-treatment: a qualitative study of older adult breast and prostate cancer survivors. *Oncology Nursing Forum*. 2015; 42(6): 358-367. doi: 10.1188/15.ONF.E358-E367.
- [52]. McNulty JA, Nail L. Cancer survivorship in rural and urban adults: a descriptive and mixed methods study. *Journal of Rural Health*. 2015; 31(3):282-291. doi: 10.1111/jrh.12106. Epub 2015 Jan 19.
- [53]. DiSipio T, Hayes SC, Newman B, Aitken J, Janda M. Does quality of life among breast cancer survivors one year after diagnosis differ depending on urban and non-urban residence? A comparative study. *Health and quality of life outcomes*. 2010; 8(3). doi:10.1186/1477-7525-8-3.
- [54]. Rogers-Clark, C. Living with breast cancer: the influence of rurality on women's suffering and resilience. a postmodern feminist inquiry. *Australian Journal of Advanced Nursing*. 2002; 20(2), 34-39.
- [55]. Rogers LQ, Goncalves L, Martin MY, Pisu M, Smith TL, Hessong D, Oster RA, Qu H, Shewchuk R, Iqbal F, Sheffield ME, Minter A, Baumann AA. Beyond efficacy: a qualitative organizational perspective on key implementation science constructs important to physical activity intervention translation to rural community cancer care sites. *Journal of Cancer Survivorship*. 2019; 13(4): 537-546. doi: 10.1007/s11764-019-00773-x.
- [56]. Reid-Arndt SA, Cox CR. Does rurality affect quality of life following treatment for breast cancer?. *The Journal of rural health: official journal of the American Rural Health Association and the National Rural Health Care Association*. 2010; 26(4): 402–405. doi:10.1111/j.1748-0361.2010.00295.x.
- [57]. Angell KL, Kreshka MA, McCoy R, Donnelly P, Turner-Cobb JM, et al. Psychosocial intervention for rural women with breast cancer: The Sierra-Stanford Partnership. *Journal of general internal medicine*. 2003;18(7): 499–507. doi:10.1046/j.1525-1497.2003.20316.x.

- [58]. López ED, Eng E, Randall-David E, Robinson N. Quality-of-life concerns of African American breast cancer survivors within rural north carolina: blending the techniques of photovoice and grounded theory. *Qualitative Health Research*. 2005; 15(1): 99–115. doi: https://doi.org/10.1177/1049732304270766.
- [59]. Torres E, Dixon C, Richman AR. Understanding the breast cancer experience of survivors: a qualitative study of african American women in rural eastern north Carolina. *J Canc Educ.* 2016; 31(1): 198-206. https://doi.org/10.1007/s13187-015-0833-0.
- [60]. Allen KR, Roberto KA. Older women in appalachia: experiences with gynecological cancer. *The Gerontologist*. 2014; 54(6): 1024–1034. doi: https://doi.org/10.1093/geront/gnt095.
- [61]. Allicock M, Haynes-Maslow L, Johnson LS, Carpenter WR, Vines AI, Belle DG et al. Peer Connect for African American breast cancer survivors and caregivers: a train-the-trainer approach for peer support. *Translational behavioral medicine*. 2017; 7(3): 495–505. doi:10.1007/s13142-017-0490-4.
- [62]. Adams N, Gisiger-Camata S, Hardy CM et al. Evaluating survivorship experiences and needs among rural African American breast cancer survivors. *Journal of Cancer Education*. 2017; 32(2): 264-271. doi: https://doi.org/10.1007/s13187-015-0937-6.
- [63]. Cahir C, Thomas AA, Dombrowski SU, Bennett K, Sharp L. Urban-rural variations in quality-of-life in breast cancer survivors prescribed endocrine therapy. *International journal of environmental research and public health*. 2017; 14(4): 394. doi:10.3390/ijerph14040394.
- [64]. Cosco TD, Kaushal A, Hardy R, Richards M, Kuh D, Stafford M. Operationalising resilience in longitudinal studies: a systematic review of methodological approaches. *Journal of Epidemiology Community Health*. 2017; 71(1): 98-104. doi: 10.1136/jech-2015-206980.
- [65]. Applebaum AJ, Breitbart W. Care for the cancer caregiver: a systematic review. *Palliat Support Care*. 2013;11(3):231-252. doi:10.1017/S1478951512000594.
- [66]. Valerio MA, Rodriguez N, Winkler P, et al. Comparing two sampling methods to engage hard-to-reach communities in research priority setting. *BMC Med Res Methodol*. 2016;16(1):146. Published 2016 Oct 28. doi:10.1186/s12874-016-0242-z.
- [67]. LeBaron VT. What is the rural cultural perspective? [commentary]. Oncology Nursing Forum. 2018;45(6):683-685. doi: 10.1188/18.ONF.683-685.
- [68]. Hamer M, Chida Y, Molloy GJ. Psychological distress and cancer mortality. *J Psychosom Res.* 2009;66(3):255-258. doi:10.1016/j.jpsychores.2008.11.002.
- [69]. Molina Y, Yi JC, Martinez-Gutierrez J, Reding KW, Yi-Frazier JP, Rosenberg AR. Resilience among patients across the cancer continuum: diverse perspectives. *Clinical journal of oncology nursing*. 2014; 18(1), 93–101. doi:10.1188/14.CJON.93-101.

- [70]. McKibbin C, Lee A, Steinman BA, Carrico C, Bourassa K, Slosser A. Health status and social networks as predictors of resilience in older adults residing in rural and remote environments. *J Aging Res.* 2016;2016:4305894. doi:10.1155/2016/4305894.
- [71]. Vaughan L, Edwards N. The problems of smaller, rural and remote hospitals: Separating facts from fiction. *Future Healthc J.* 2020;7(1):38–45. doi:10.7861/fhj.2019-0066
- [72]. Porter KJ, Brock DJ, Estabrooks PA, et al. SIPsmartER delivered through rural, local health districts: adoption and implementation outcomes. *BMC Public Health*. 2019;19(1):1273. Published 2019 Sep 18. doi:10.1186/s12889-019-7567-6.
- [73]. Pascal J, Johnson N, Dickson-Swift V, Kenny A. Returning home: psychosocial care during the re-entry phase of cancer survivorship in rural Australia. *European Journal of Cancer Care*. 2014;24(1):39-49. doi: https://doi.org/10.1111/ecc.12232.
- [74]. Katz ML, Reiter PL, Corbin S, de Moor JS, Paskett ED, Shapiro CL. Are rural Ohio Appalachia cancer survivors needs different than urban cancer survivors?. *Journal of Cancer Survivorship: Research and Practice*. 2010;4(2): 140–148. doi:10.1007/s11764-010-0115-0
- [75]. Phillips M. Assets and affect in the study of social capital in rural communities. *Sociol Ruralis*. 2016;56(2):220–247. doi:10.1111/soru.12085.
- [76]. Schoenberger, Y. M., Benz, R., McNees, P., & Meneses, K. Patient-centered outcome evaluation of the Rural Breast Cancer Survivors Intervention. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer.* 2016; *24*(4):1841–1848. doi:10.1007/s00520-015-2974-4.
- [77]. DeGuzman PB, Bernacchi V, Cupp CA, et al. Beyond broadband: digital inclusion as a driver of inequities in access to rural cancer care [published online ahead of print, 2020 May 11]. *J Cancer Surviv*. 2020;10.1007/s11764-020-00874-y. doi:10.1007/s11764-020-00874-y.
- [78]. Denzin, NK, Giardina, M.D. *Qualitative inquiry and human rights*. Walnut Creek, CA: Left Coast Press; 2010.
- [79]. Ellis C. Emotional and ethical quagmires in returning to the field. *Journal of Contemporary Ethnography*. 1995;24(1): 68-98.
- [80]. Ellis C, Bochner AP. Composing ethnography: Alternative forms of qualitative writing. Walnut Creek, CA: AltaMira Press; 1996.
- [81]. Emerson RM, Fretz RI, Shaw LL. Writing ethnographic fieldnotes. Chicago, IL: University of Chicago Press; 1995.
- [82]. Foley DE. Critical ethnography: The reflexive turn. *International Journal of Qualitative Studies in Education*. 2002;15(4), 469-490.

- [83]. Madison DS. *Critical ethnography: Method, ethics, and performance*. Thousand Oaks, CA: SAGE Publications; 2005.
- [84]. Smith CA, Gallo AM. Applications of performance ethnography in nursing. *Qualitative Health Research*. 2007;17(4): 521-528.
- [85]. Smyth W & Holmes C. Using Carspecken's critical ethnography in nursing research. *Contemporary Nurse*. 2005; 19(1-2):65-74.
- [86]. Mettler M, Stone W, Herrick A, Klein D. Evaluation of a community-based physical activity campaign via the transtheoretical model. *Health Promot Pract*. 2000;1(4):351–359.
- [87]. Wallerstein NM, Duran B. Using community-based participatory research to address health disparities. Health Promotion Practice. 2006;7(3):312-323. doi:10.1177/1524839906289376.
- [88]. Isler MR, Miles MS, Banks B, Perreras L, Muhammad M, Parker D, Corbie-Smith G. Across the miles: process and impacts of collaboration with a rural community advisory board in HIV research. *Progress in Community Health Partnerships: Research, Education, and Action*. 2015;9(1): 41–48. doi: https://doi.org/10.1353/cpr.2015.0014.
- [89]. Duijts SF, Faber MM, Oldenburg HS, van Beurden M, Aaronson NK. Effectiveness of behavioral techniques and physical exercise on psychosocial functioning and health-related quality of life in breast cancer patients and survivors—A meta-analysis. *Psycho-Oncology*. 2011;20:115–126. doi: 10.1002/pon.1728.
- [90]. Loprinzi CE, Prasad K, Schroeder DR, Sood A. Stress management and resilience training (SMART) program to decrease stress and enhance resilience among breast cancer survivors: A pilot randomized clinical trial. *Clinical Breast Cancer*. 2011;11:364–368. doi: 10.1016/j.clbc.2011.06.008.
- [91]. Lee V, Robin Cohen S, Edgar L, Laizner AM, Gagnon AJ. Meaning-making intervention during breast or colorectal cancer treatment improves self-esteem, optimism, and self-efficacy. *Social Science and Medicine*. 2006;62:3133–3145. doi: 10.1016/j.socscimed.2005.11.041.
- [92]. Dulko D, Pace CM, Dittus KL, Sprague BL, Pollack LA, Hawkins NA., Geller BM. Barriers and facilitators to implementing cancer survivorship care plans. *Oncology nursing forum*. 2013;40(6): 575–580. doi: https://doi.org/10.1188/13.ONF.575-580.
- [93]. Deshields TL, Heiland, ML, Kracen AC, Dua P. Resilience in adults with cancer: development of a conceptual model. *Pscyhooncology*. 2016; 25: 11-18. doi: 10.1002/pon.3800.
- [94]. Zahnd WE, Jenkins WD, Shackelford J, Lobb R, Sanders J, Bailey A. Rural cancer screening and faith community nursing in the era of the affordable care act. *Journal of Health Care for the Poor and Underserved*. 2018;29(1): 71-80. doi: 10.1353/hpu.2018.0008.

- [95]. Averill JB. Studies of rural elderly individuals: merging critical ethnography with community-based action research. *Journal of Gerontological Nursing*. 2005:11-18.
- [96]. Carriere R, Adam, R, Fielding, S, Ong, Y, Murchie P. Rural dwellers are less likely to survive cancer-an international review and meta-analysis. *Health & Place*. 2018;53:219-227. doi: https://doi.org/10.1016/j.healthplace.2018.08.010.
- [97]. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field Methods*. 2006; 18: 59-82. doi: 10.1177/1525822X05279903.
- [98]. Hagaman AK, Wutich A. How many interviews are enough to identify metathemes in multisited and cross-cultural research? Another perspective on Guest, Bunce and Johnson's (2006) landmark study. *Field Methods*. 2017;29:23-41.
- [99]. Belone L, Lucero JE, Duran B, et al. Community-Based Participatory Research Conceptual Model: Community Partner Consultation and Face Validity. *Qual Health Res.* 2016;26(1):117-135. doi:10.1177/1049732314557084.
- [100]. Newman SD, Andrews JO, Magwood GS, Jenkins C, Cox MJ, Williamson DC. Community advisory boards in community-based participatory research: a synthesis of best processes. *Preventing Chronic Disease*. 2011;8(3). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3103575/.
- [101]. Graves BA, Hamner K, Nikles S, Wells H. Use of community-based participatory research toward eliminating rural health disparities. *Online Journal of Rural Nursing and Health Care*. 2015;15(2): 63-87. doi: http://dx.doi.org/ 10.14574/ojrnhc.v15i2.353.
- [102]. Hennink MM, Kaiser BN, Weber MB. What influences saturation? estimating sample sizes in focus group research. *Qual Health Res.* 2019;29(10):1483-1496. doi:10.1177/1049732318821692.
- [103]. Thomas J. Doing critical ethnography qualitative research methods Series Sage 26. Newbury Park CA: SAGE publications; 1993.
- [104]. DePoy E, Gitlin LN. Naturalistic Designs, in Introduction to Research 5ed. St. Louis MI: Elsevier; 2016.
- [105]. Hine C. Virtual Ethnography. Thousand Oaks CA: SAGE Publications; 2000.
- [106]. Geertz C. The interpretation of cultures. New York NY: Basic Books; 1973.
- [107]. Emerson RM. Contemporary field research perspectives and formulations. Prospect Heights IL: Waveland Press; 2001.

- [108]. Emerson RM, Fretz R, Shaw L. Writing ethnographic fieldnotes. Chicago: The University of Chicago Press; 1995.
- [109]. Morse JM. Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research*. 2015;25:1212-1222. 10.1177/1049732315588501.
- [110]. Emerson RM, Fretz RI Shaw LL. Writing ethnographic field notes. Chicago: University of Chicago Press; 2011.
- [111]. Lincoln YS & Guba EG. Naturalistic Inquiry. SAGE publications; 1985. bur
- [112]. Wolcott HF. The art of fieldwork. Walnut Creek CA: AltaMira Press: 2005.
- [113]. Where is southwest virginia? http://www.virginiaplaces.org/regions/15southwest.html. Published 2004. Accessed May 23, 2020.
- [114]. Gilmore N. New report: Southwest Virginia still needs greater access to healthcare services [public radio]. https://www.wvtf.org/post/new-report-southwest-virginia-still-needs-greater-access-healthcare-services#stream/0. Published 2019. Accessed June 2, 2020.
- [115]. Snyder A, Milbrath G. Description of healthcare needs at an episodic clinic in rural southwest Virginia. *Rural and Remote Health*. 2013; 13: 2557. Retrieved from www.rrh.org.au/journal/article/2557.
- [116]. Zoellner JM, Hedrick VE, You W, et al. Effects of a behavioral and health literacy intervention to reduce sugar-sweetened beverages: a randomized-controlled trial. *Int J Behav Nutr Phys Act.* 2016;13:38. Published 2016 Mar 22. doi:10.1186/s12966-016-0362-1.
- [117]. Burnett C, Bullock L, Collins CA, Hauser L. Evaluation of a clinical cancer trial research training workshop: helping nurses build capacity in southwest Virginia. *Public Health Nurs*. 2016;33(6):565-572. doi:10.1111/phn.12295.
- [118]. Bouzaher MH, Miller TK. Proper disposal of prescription opioids in southwest Virginia: assessment of patient, physician, and medical student beliefs and practices. *J Public Health Manag Pract*. 2020;26(3):259-269. doi:10.1097/PHH.000000000001153.
- [119]. Lane HG, Porter KJ, Hecht E, Harris P, Zoellner JM. A participatory process to engage Appalachian youth in reducing sugar-sweetened beverage consumption. *Health Promot Pract*. 2019;20(2):258-268. doi:10.1177/1524839918762123.
- [120]. Marzorati, C., Riva, S. & Pravettoni, G. Who Is a cancer survivor? a systematic review of published definitions. *J Canc Educ*. 2017: 32: 228–237. doi: https://doi.org/10.1007/s13187-016-0997-2.

- [121]. Ratcliffe M, Burd C, Holder K, Fields A. *Defining rural at the U.S. census bureau American community survey and geography brief.* 2016. Retrieved from https://www.census.gov/content/dam/Census/library/publications/2016/acs/acsgeo-1.pdf.
- [122]. Corwin E, Redeker NS, Richmond TS, Docherty SL, Pickler RH. Ways of knowing in precision health. *Nurs Outlook*. 2019;67(4):293-301. doi:10.1016/j.outlook.2019.05.011
- [123]. Partners for Rural Transformation. Transforming persistent poverty in rural America: How community development financial institutions drive economic opportunity [issue brief]. https://fahe.org/wp-content/uploads/Policy-Paper-PRT-FINAL-11-14-19.pdf. Published 2019. Accessed June 2, 2020.
- [124]. Kozhimannil KB, Henning-Smith C. Racism and health in rural America. *Journal of Health Care for the Poor and Underserved*. 2018; 29(1).
- [125]. Garcia MC, Faul M, Massetti G, Thomas CC, Hong Y, Bauer UE, Iademarco MF. Reducing potentially excess deaths from the five leading causes of death in the rural United States. *Morbidity and Mortality Weekly Report. Surveillance Summaries (Washington, D.C.:* 2002). 2017; 66(2), 1–7. doi:10.15585/mmwr.ss6602a1.
- [126]. Feeding Southwest Virginia Food Insecurity 2017. https://www.faswva.org/home/about-us/how-we-work/food-insecurity-2017/. Published 2017. Accessed June 5, 2020.
- [127]. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*. 1998;19:173–202. doi: 10.1146/annurev.publhealth.19.1.173.
- [128]. [138]. Allen ML, Culhane-Pera KA, Pergament S, Call KT. A capacity building program to promote CBPR partnerships between academic researchers and community members. *Clinical and Translational Science*. 2011;4(6): 428–433. https://doi.org/10.1111/j.1752-8062.2011.00362.x.
- [129]. Brock DP, Estabrooks PA, Hill JL, et al. Building and sustaining community capacity to address childhood obesity: A 3-Year mixed-methods case study of a community-academic advisory board. *Fam Community Health*. 2019;42(1):62-79. doi:10.1097/FCH.0000000000000212
- [130]. LeBaron V, Beck SL, Black F, Palat G. Nurse moral distress and cancer and pain management an ethnography of oncology nurses in india. *Cancer Nursing*. 2014; 3(5): 331-344. doi: 10.1097/NCC.00000000000013.
- [131]. Zoellner J, Chen Y, Davy B, et al. Talking health, a pragmatic randomized-controlled health literacy trial targeting sugar-sweetened beverage consumption among adults: rationale, design & methods. *Contemp Clin Trials*. 2014;37(1):43-57. doi:10.1016/j.cct.2013.11.003.

- [132]. Lebaron V, Beck SL, Maurer M, Black F, Palat G. An ethnographic study of barriers to cancer pain management and opioid availability in India. *Oncologist*. 2014;19(5):515-522. doi:10.1634/theoncologist.2013-0435.
- [133]. Belotto MJ. Data analysis methods for qualitative research: managing the challenges of coding, interrater reliability and thematic analysis. *The Qualitative Report*. 2018;23(11):2622-2633.
- [134]. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2);77-101. Doi: http://dx.doi.org/10.1191/1478088706qp063oa.
- [135]. Saldena J. The coding manual for qualitative researchers. Thousand Oaks CA: SAGE publications: 2013.
- [136]. DePriest KN, Shields TM, Curriero FC. Returning to our roots: The use of geospatial data for nurse-led community research. *Res Nurs Health*. 2019;42(6):467-475. doi:10.1002/nur.21984.
- [136]. LeBaron V, Beck SL, Black F, Palat G. Nurse moral distress and cancer and pain management an ethnography of oncology nurses in india. *Cancer Nursing*. 2014; 3(5): 331-344. doi: 10.1097/NCC.00000000000013.
- [137]. Schootman M, Gomez SL, Henry KA, et al. Geospatial Approaches to Cancer Control and Population Sciences. *Cancer Epidemiol Biomarkers Prev.* 2017;26(4):472-475. doi:10.1158/1055-9965.EPI-17-0104.
- [138]. Champion VL, Christy SM, Rakowski W, et al. A Randomized Trial to Compare a Tailored Web-Based Intervention and Tailored Phone Counseling to Usual Care for Increasing Colorectal Cancer Screening. *Cancer Epidemiol Biomarkers Prev.* 2018;27(12):1433-1441. doi:10.1158/1055-9965.EPI-18-0180.
- [139]. Reblin M, Heyman RE, Ellington L, Baucom BRW, Georgiou PG, Vadaparampil ST. Everyday couples' communication research: Overcoming methodological barriers with technology. *Patient Educ Couns.* 2018;101(3):551-556. doi:10.1016/j.pec.2017.10.019.

## Chapter 3

## Title

Rural Resilience in Cancer Survivors: Conceptual Analysis of a Global Phenomena

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#### Abstract

**Purpose:** Rural culture may negatively or positively impact the psychosocial health of rural cancer survivors. When rural cancer survivors utilize aspects of rural culture to enable positive adaptations, they demonstrate the phenomenon of rural resiliency. However, resiliency in cancer survivors, and in rural communities, is poorly understood. The purpose of this analysis is to identify the concept of rural resiliency in cancer survivors in the nursing literature and propose a conceptual framework that may help nurses leverage resilience to improve rural survivorship care. Methods: We used Walker & Avants' concept analysis method to direct the selection and analysis of research articles published between 2000 and 2020 that focused on cancer survivors residing in rural communities. We identified a definition, antecedents, consequences, attributes, and empirical referents, and related terms. We developed model, contrary, and borderline case examples. A novel conceptual framework incorporating these attributes is proposed. **Conclusions:** The conceptual model of rural resiliency for cancer survivors is grounded in three domains of rural culture, each with attributes that may impact rural resiliency: spirituality, cultural norms, and social capital. These domains impact a cancer survivor's status on the continuum of rural resilience-psychosocial distress, leading to either negative or positive psychosocial outcomes. Clinical Relevance: A better understanding of how rural resiliency impacts cancer survivors can help clinicians and researchers provide feasible and culturallytargeted post-treatment care. The proposed conceptual framework guides nurse researchers to develop culturally appropriate measurement tools and evaluate rural resiliency and its impact on outcomes. Nurses with a better understanding of resilience in rural cancer survivors can ultimately reduce health outcome disparities and improve access to supportive care resources.

**Key words:** rural, cancer survivor, resilience, concept analysis, conceptual framework

## Rural Resilience in Cancer Survivors: Conceptual Analysis of a Global Phenomena

There are over 43.8 million cancer survivors worldwide (American Cancer Society, 2018), and approximately 3.4 billion people living in rural communities (World Bank, 2018). Globally, rural cancer survivors may experience greater psychosocial distress (distress due to physical, emotional, or mental pressures that can decrease quality of life in cancer survivors; National Cancer Institute, 2020) compared to urban cancer survivors (Butow et al., 2012). In countries such as Australia, the U.S., Ireland, and the U.K., rural cancer survivors face barriers to psychosocial care such as provider shortages, local hospital closures, and greater travel times to health care facilities (Butow et al; Rogers-Clack, 2002). Additional barriers include low socioeconomic status, lack of health insurance, and mistrust in healthcare providers (Zahnd et al, 2018; Rogers-Clark, 2002). Further complicating access to psychosocial care, rural cancer survivors may prefer to seek psychosocial support from informal sources such as family, friends, and community members instead of healthcare providers (Pascal, Johnson, & Dickson-Swift, 2015). The global body of literature has identified negative outcomes that rural cancer survivors experience, such as decreased quality of life (National Cancer Institute, 2012), but little is known about how rural cancer survivors make positive adaptations to improve health outcomes (Katz et al, 2010). This concept analysis will help introduce the novel phenomena of rural resilience in cancer survivors by describing how rural survivors adapt their available community resources to obtain psychosocial care and improve their health outcomes (Cosco, Kaushal, Hardy, Richards & Stafford, 2017).

Resiliency in cancer survivorship is poorly understood due to multiple definitions and contexts (Molina et al, 2018). The concept of *rural resilience* is scarce in nursing literature, and

in cancer survivorship literature. At this point, resilience is ill-understood in rural communities, likely because of a strong focus on the negative outcomes that cancer survivors experience (Rogers-Clark, 2002). Concepts are dependent on their context (Rodgers & Knafl, 1993) and resiliency in cancer survivors needs to be analyzed from the rural cultural perspective. Currently, rural resilience is a developmental concept in ecological literature (Heijman, Hagelaar & van der Heide, 2019) but this concept may not depict how rural cancer survivors make positive adaptations despite poor healthcare access. Likewise, resilience has been analyzed as a concept in nursing literature for patients across the age continuum (Earvolino-Ramirez, 2007) but that model may not capture how rural culture influences resiliency, or how nursing research may utilize resiliency to improve health outcomes for rural cancer survivors. Resilience in adult cancer survivors has been conceptualized in a model that explains the continuum of distressresilience and incorporated individual characteristics (Deshields, Heiland, Kracen & Dua, 2016) but does not explain the role of culture. Rural culture influences the health behaviors and beliefs of cancer patients, and its role needs to be understood to develop interventions that improve health outcomes (Carriere et al, 2018; Rogers et al, 2019). Developing a conceptual framework of rural resiliency is the first step towards future intervention development.

By understanding the attributes and outcomes of rural resiliency in cancer survivors, clinical nurses and researchers working in a variety of rural settings will be able to better identify how to engage their communities in survivorship care to improve health outcomes. The purpose of this concept analysis is to 1) establish rural resilience in cancer survivors as a global phenomena of nursing interest, and 2) propose a conceptual framework to guide the development of interventions that promote rural resilience in cancer survivors. The concept of rural resilience in cancer survivors will be analyzed using the Walker & Avant method while discussing the

challenges of measuring rural resilience, and recommending focus areas for future research (Schiller, 2018)

#### Methods

A clear and rigorous concept analysis is fundamental for future nursing theory and clinical practice changes (Schiller 2018). To accomplish this, we selected the Walker and Avant's method due to its prevalence in nursing concept literature and clear methodological steps (Walker & Avant, 2005).

The selection of rural resilience in cancer survivors was chosen based on our clinical experiences observing this population's successful adaptations to meet their post-treatment needs through informal community resources. The literature defines adaptation in the face of adversity as resiliency (Cosco et al, 2017). In this analysis, rural resilience is defined as 1) rural cancer survivors facing adversity, and 2) making an adaption, specifically the use of informal community resources to meet post-treatment care needs and overcome structural, social, physical, and cultural barriers to accessing healthcare.

The purpose of this concept analysis is to identify the phenomena of rural resiliency in the cancer survivorship literature. Language used to describe resiliency in the literature guided the search in two phrases. The first search phrase used (resilience OR self-efficacy OR coping OR resiliency OR self-reliance OR spirit OR strength OR "positive adaptation") AND rural AND cancer AND survivor. The second phrase used community AND rural AND cancer AND survivor. Databases searched were: PubMed, GoogleScholar, Proquest Social Sciences, and Web of Science. 165 studies were retrieved. All studies retrieved by the search phrases were exported to citation manager Mendeley for title and abstract review. Studies that were relevant to the conceptual analysis based on title and abstract review were fully read, and concept uses,

antecedents, consequences, and empirical referents were coded and extracted by a single reviewer. 29 studies meet inclusion criteria for this conceptual analysis.

#### Analysis

# **Concept Uses**

The literature reflects a continuum of positive and negative aspects of rural resilience as it relates to psychosocial outcomes. Negative aspects that increased psychosocial distress included: describing inaccurate beliefs about cancer (Livaudais et al, 2010); explaining how rurality caused poor health outcomes (Katz et al, 2010); describing how rural cancer survivors ended up isolated from their communities (Rogers-Clark, 2002); and describing a lack of care-seeking behaviors (Gunn et al, 2020). Positive aspects of the concept included: strong coping strategies (Cahir, Thomas, Dombrowski, Bennett & Sharp, 2017); inner strength (Gunn et al, 2020); informal community support systems (Allicock et al, 2017); changing negatives into positives (Gisigeramata, Adams, Nolan & Meneses, 2016); improved health outcomes (Rogers et al, 2019); buffers to emotional distress (Reid-Arndt & Cox, 2010); reduced distress (Angell et al, 2003); maintaining social standing during survivorship (López, Eng, Randall-David & Robinson, 2005); improved self-efficacy (Olson et al, 2014); returning to normalcy (Torress, Dixon & Richman, 2016) a positive survivorship narrative (Allen & Roberto, 2014).

#### Antecedents

Several antecedents were consistently found during the phenomena of rural resilience in cancer survivors. These included barriers to health care access and health outcome disparities, unmet needs for caregivers, fear, having a goal of returning to normal, and a lack of survivorship information (DeGuzman, Colliton, Nail & Keim-Malpass, 2017). The dearth of healthcare access caused a cascade of issues such as unmet survivor needs, fear of cancer-related outcomes, and

lack of available survivorship information. Facing these challenges, rural survivors needed to find survivorship care through the community resources available to them.

#### Attributes

Rural resilience is guided by cultural beliefs and values. Resiliency exists on a dynamic continuum of resilience-psychosocial distress (Deshields et al, 2016), and culture impacts resilience through subjective norms and health behaviors (Carriere et al, 2018). We found the rural cultural domains of spirituality, social capital, and cultural norms have aspects that can positively or negatively impact health along the resilience-psychosocial distress continuum. The attributes are presented here as a dichotomy between those positive aspects (such as seeking support from the community), and related negative aspects (such as mistrust in healthcare). Spirituality: Faith vs Fatalism. Rural cancer survivors face challenges obtaining information about the survivorship period, including what to expect. Rural survivors use faith as a source of cancer knowledge and support, using spiritual explanations such "God's will (Livaudais et al, 2010)." Faith, prayer, and God are linked to strong social networks via local community churches, and this spiritual support can enable rural cancer survivors to remain positive during the survivorship transition (Torres et al. 2016). Through faith and spiritual knowledge, which supports inner-strength, rural survivors maintain their independence (Walker, Szanton, & Wenzel, 2015). Faith is utilized as a channel for rural cancer survivors to return to their community; rural cancer survivors determined they were successfully transitioning back to their normal lives by spending time at church instead of in the hospital (Walker et al, 2015).

The negative aspect of spirituality was fatalism. With the spiritual knowledge of "God's will," rural survivors may accept their pre-determined fate and decide not to seek health care (Torres et al, 2016; Livaudais et al, 2010). Through fatalism, spiritual knowledge of cancer is the

result of poorly resourced communities and cultural oddities (Allen et al, 2014). Providers' own perceptions of spiritual beliefs may result in culturally inappropriate care.

Social Capital: Strong Community Networks vs Cultural Differences. The attribute of strong social networks was frequently used to describe rural communities in research literature. Terms used to describe social networks include "support networks," "community," and "social support (Rogers et al, 2019, Olson et al, 2014; Torres et al, 2016)". Rural cancer survivors utilize their strong social networks as both informal community support systems and caregivers. Social networks keep community members closely connected, and therefore survivors' cancer journeys are often public knowledge, which survivors view both positively and negatively (McNulty & Nail, 2015). Despite a loss of privacy, communities support rural cancer survivors to make healthy choices (Rogers et al, 2019), and make healthcare related decisions (Allen et al, 2014).

The presence and role of strong social networks in rural communities positively impact survivors' health, but cultural differences may transmit false thinking and beliefs about cancer. The term "cultural differences" was used to encompass any cancer-related belief, activity, or value that was not congruent with mainstream medical practice. Cultural differences were used to explain rural survivors' inaccurate beliefs about cancer, unhealthy patterns of behavior, and reasons for worse mental health outcomes (Livaudais et al, 2010; Andrykowski & Burris, 2010). *Cultural Norms: Seeking community support vs mistrust in healthcare providers.* Rural cancer survivors often prefer to seek support from informal community sources instead of formal health providers (Pascal et al, 2015). Rural cancer survivors seek the opportunity to connect with community peers, and obtain community support (Allicock et al, 2017). Rural cancer survivors indicate they trust their community and community leaders and feel a strong desire to reconnect

with their community as they transition to back to their normal lives (Gunn et al, 2020; McNulty & Nail, 2015).

However, seeking community care may also be due to culturally grounded mistrust in healthcare providers, particularly for rural ethnic and minority groups. Rural cancer survivors are sometimes unwilling to seek care from providers (Rogers-Clark, 2002). A negative outcome of seeking survivorship care and information from informal community sources, is that rural cancer survivors learn inaccurate beliefs about cancer (Livaudais et al, 2010). Minority survivors are at particular risk of experiencing negative outcomes due to cultural differences when interacting with the health care system (López et al, 2005; McNulty & Nail, 2015).

## Consequences

Consequences of rural resilience for cancer survivors is associated positive and negative outcomes along the resilience-psychosocial distress continuum. Resilient rural cancer survivors can leverage self-and community-reliance to their benefit, but limited healthcare facility resources can lead to unmet post-treatment needs.

Rural cancer survivors who adapted their existing community systems to support their needs experienced positive consequences such as improved quality of life (McNulty & Nail, 2015), improved physical health (Rogers et al, 2019), decreased psychological distress (Angell et al, 2003), strong coping skills (Torres et al, 2016), improved self-efficacy (Olson et al, 2014), less emotional distress (Reid-Arndt & Cox, 2016), and post-traumatic growth (Andrykowski & Burris, 2010). Despite the lack of available health care providers and information, rural cancer survivors were able to utilize their informal community resources to improve their health outcomes.

When aspects of rural culture impacted health behaviors in a way that decreased rural resiliency and increased psychosocial distress, cancer survivors experienced chronic health crisis (Rogers-Clark, 2002), lower functionality (Reid-Arndt & Cox, 2010), unmet survivorship needs (Katz et al, 2010), worse coping skills (Schlegel, Talley, Molix & Bettencourt, 2009), and poorer psychosocial health (Andrykowski & Burris, 2010). In context of these negative attributes, although rural cancer survivors adapt their strong informal community support systems to obtain survivorship care, they experience poorer health outcomes because they lack clinical support (Pascal et al, 2015).

## Model, Borderline, and Contrary Cases

In a model case of rural resiliency, cancer survivors with poor access to providers obtain survivorship care efficiently using informal community resources. For example, Jackie, a 57-year old breast cancer survivor, is six months post treatment. She received her cancer treatment from a NCI-designated cancer center that is two hours away from her home. Her local hospital does not have an oncologist or social worker, and her primary care physician is not comfortable providing survivorship care. Jackie is experiencing high levels of anxiety about her physical and functional changes post treatment. She seeks information and support from peers at her church group. Using her social network and spiritual knowledge, Jackie views her new changes as "God's will" and experiences reduced levels anxiety. She does not seek clinical support or treatment. At her follow up visit with her oncologist, Jackie admits to having anxiety, but declines her oncologist's offer for a social work referral.

A borderline case of rural resiliency would be if a cancer survivor sought information or support from informal community resources, but is unable to efficiently obtain help. Using the same situation as described above, a borderline case of resiliency would be if Jackie seeks knowledge and support from her local church group, but the church group is difficult for her to connect with. It takes Jackie several attempts before she is able to speak with the church group, but once she does, they give her information and support.

In a contrary case, consider James, a 70-year old thyroid cancer survivor who has been denied help from an informal community network. James received treatment from an oncologist and surgeon at the nearest Cancer Center-over 2.5 hours away from his home. He needs to make a follow-up appointment with an endocrinologist, but there is only one provider in his community, and the provider doesn't have any appointments available for the next three months. James will need to travel back to the Cancer Center in a week to see the Endocrinologist there, but he is unable to drive because of the pain medications he is taking. James needs help with transportation to his appointment. He reaches out to his local community, friends and neighbors, and they tell him they cannot help him. James has to reschedule his appointment.

## **Empirical Referents**

Although the phenomenon of rural resilience is present in the literature, the conceptual term is not. Likewise, there are currently no consistently used empirical referents of rural resilience. While there are various resiliency measures, the Connor-Davidson Resilience scale and Resilience Scale for adults were found most frequently in our literature review, and both have higher psychometric ratings when compared to other resilience measures (Wells, 2009). The Resilience Scale has been used to assess resilience in rural cancer survivors, and found that the scale may not show how self-reliance in rural communities is possible due to the presence of strong social networks (Wells, 2009). The Resilience Scale for Adults measures resilience through the domains of personal competence, social competence, family coherence, social support and personal structure (Wells, 2009). When compared to the domains we found to

impact rural resiliency, this scale measured social capital thoroughly. However, it may not measure the rural resilience domains of spirituality and cultural norms.

The Connor-Davidson Resilience Scale, a reliable and validated scale used to measure resiliency in cancer patients across the care continuum (Connor & Davison, 2003) has been used to assess resiliency in aging rural populations (McKibbin et al, 2016). This scale measures resilience through the domains of personal competence, trust, acceptance of change and secure relationships, control, and spiritual influence (Wells, 2009). When compared to our findings regarding rural resilience, this scale may addresses the domain of spirituality, and may address social capital through relationship, personal competence and secure relationships. However, the Connor-Davidson Resilience Scale does not factor in the impact of cultural norms, which we found to be a significant domain of rural resiliency.

Neither the Connor-Davidson Resilience Scale or the Resilience Scale of Adults comprehensively measure the domains of rural resilience found in our literature review. Furthermore, it is unknown if these scales are culturally appropriate for rural cancer survivors (Wells, 2009). Resilience may be understood differently within various cultures (Wells, 2009) and we have established that rural culture is the foundation of rural resilience for cancer survivors through our analysis. Future qualitative research can determine the applicability of current resilience measures, and provide direction for how to improve those measures to be culturally tailored (Wells, 2009).

#### **Discussion**

We have identified rural resiliency within the literature by discovering how rural cancer survivors achieve health in a limited-resource environment. We found rural survivors experience more cancer-related fears, unmet needs, and higher levels of emotional distress than urban ones

(Gunn et al, 2020). Due to cultural beliefs, personal preference, or lack of resources, rural survivors actively seek survivorship care through informal community systems (Pascal et al, 2015). While rural survivors demonstrate resiliency, the unique cultural context makes it challenging to define or measure rural resiliency. Rural cancer survivor needs are different from urban ones, and require different interventions (Katz et al, 2010).

We propose a conceptual framework to aid in understanding the role of rural resiliency when addressing the unique needs of rural cancer survivors. Figure 1 depicts a conceptual framework of rural resilience based on the current analysis. This framework depicts attributes of rural resiliency found within the literature, which are represented as three cultural domains on the resilience-psychosocial distress continuum (Deshilds et al, 2016). The domains of spirituality, social capital and cultural norms can impact resilience in rural cancer survivors. We found that within the domain of spirituality, faith may be used to increase inner-strength (Allen & Roberto, 2014), while fatalism can hinder coping (Schlegel et al, 2009). In the domain of social networks, strong community networks provide and acceptable source of support (Allicock et al, 2017), which may help strengthen self-efficacy (Olson et al, 2014). However, cultural differences may be contributed to the decision not to seek care (Gunn et al, 2020), particularly for ethnic and minority cancer survivors (López et al, 2005; Torres et al, 2016; Livaudais et al, 2010). In the domain of cultural norms, the rural cancer survivors seek information through trusted community knowledge and resources (Allicock et al, 2017), but rural patients may not seek formal provider care due to mistrust of providers (Rogers-Clark, 2002).

The attributes of each domain impact rural resiliency along the resiliency-psychosocial distress continuum (Deshilds et al, 2016). Increased resilience leads to improved psychosocial outcomes, such as quality of life, coping, self-efficacy and posttraumatic growth. Less resilience

leads to increased psychosocial distress and worse psychosocial outcomes, including poor quality of life, more unmet needs, and poor coping skills.

RURAL RESILIENCE

Faith SPIRITUALITY Fatalism

Community Networks SOCIAL CAPITAL Cultural Differences

Trust in Community CULTURAL NORMS Mistrust of Providers

Improved Quality of Life Improved Coping skills Increased Self-efficacy More Post-traumatic Growth

Poor Psychosocial health

Figure 1 Conceptual Framework for Rural Resilience in Cancer Survivors

Psychosocial Outcomes

By investigating both positive and negative impacts of rural culture on cancer survivor resilience, nurse scientists can broaden the understanding of how rurality can positively impact health. Targeted interventions to strengthen resiliency has led to improved health outcomes for cancer survivors (Molina et al, 2014). Researchers have already successfully utilized community-based interventions to improve survivorship care (Angell et al, 2003). Nurses are ideally positioned to improve psychosocial distress in rural cancer survivors by promoting rural resiliency. Rural communities highly value nursing care, and that nurse-driven interventions improve outcomes for rural cancer survivors (Schoenberger et al, 2016; American Cancer Society, 2018). In fact, some rural cancer survivors have claimed that the ability to speak with their nurse is the most valuable aspect of survivorship care (Schoenberger et al, 2016).

Moving forward, our conceptual framework may be used to help clinicians and researchers support rural cancer survivors by identifying domains that are supporting or detracting from patients' health, aligning patient and family education to relevant domains, and directing patients to community resources that will support health. Nurse researchers can use the

conceptual framework to develop targeted interventions within the domain areas to support rural cancer survivors, and use the framework to identify measurable variables. Nurse researchers can also use the conceptual model to guide future qualitative research that can evaluate the cultural appropriateness of current resilience measures, and to develop and evaluate a comprehensive measure of rural resilience (Wells et al, 2009).

#### **Chapter 3 References**

#### Reference List

- Adams, N., Gisiger-Camata, S., Hardy, C.M. et al. (2017). Evaluating survivorship experiences and needs among rural african american breast cancer survivors. *Journal of Cancer Education*, 32(2), 264-271. doi: https://doi.org/10.1007/s13187-015-0937-6.
- Allen, K.R., & Roberto, K.A. (2014). Older women in appalachia: experiences with gynecological cancer. *The Gerontologist*, *54*(6), 1024–1034. doi: https://doi.org/10.1093/geront/gnt095.
- Allicock, M., Haynes-Maslow, L., Johnson, L. S., Carpenter, W. R., Vines, A. I., Belle, D. G., ... Cherry, M. W. (2017). Peer connect for african american breast cancer survivors and caregivers: a train-the-trainer approach for peer support. *Translational behavioral medicine*, 7(3), 495–505. doi:10.1007/s13142-017-0490-4.
- Andrykowski, M. A., & Burris, J. L. (2010). Use of formal and informal mental health resources by cancer survivors: differences between rural and nonrural survivors and a preliminary test of the theory of planned behavior. *Psycho-oncology*, *19*(11), 1148–1155. doi:10.1002/pon.1669.
- Angell, K. L., Kreshka, M. A., McCoy, R., Donnelly, P., Turner-Cobb, J. M., Graddy, K., ...

  Koopman, C. (2003). Psychosocial intervention for rural women with breast cancer: The Sierra-Stanford Partnership. *Journal of general internal medicine*, *18*(7), 499–507.

  doi:10.1046/j.1525-1497.2003.20316.x.
- American Cancer Society. (n.d.). *The cancer atlas*. Retrieved from https://canceratlas.cancer.org/the-burden/cancer-survivorship/.

- Butow, P.N., Phillips, F., Schweder, J. et al. (2012). Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: a systematic review. *Support Care Cancer*, 20(1). doi: https://doi.org/10.1007/s00520-011-1270-1.
- Cahir, C., Thomas, A. A., Dombrowski, S. U., Bennett, K., & Sharp, L. (2017). Urban-rural variations in quality-of-life in breast cancer survivors prescribed endocrine therapy. *International Journal of Environmental Research and Public Health*, *14*(4), 394. doi:10.3390/ijerph14040394.
- Carriere R., Adam, R., Fielding, S., Ong, Y., & Murchie P. (2018). Rural dwellers are less likely to survive cancer-an international review and meta-analysis. *Health & Place*, 53, 219-227. doi: https://doi.org/10.1016/j.healthplace.2018.08.010.
- Connor, KM, & Davidson, JR.(2003). Development of a new resilience scale: the connor-davidson resilience scale (cd-risc). *Depression and Anxiety*, 18(2) 76-82.
- Cosco, T.D., Kaushal, A., Hardy, R., Richards, M., Kuh, D., & Stafford, M. (2017).

  Operationalising resilience in longitudinal studies: a systematic review of methodological approaches. *Journal of Epidemiology Community Health*, 71(1), 98-104. doi: 10.1136/jech-2015-206980.
- Coyne, C. A., Demian-Popescu, C., & Friend, D. (2006). Social and cultural factors influencing health in southern West Virginia: a qualitative study. *Preventing chronic disease*, *3*(4), A124.
- DeGuzman, P., Colliton, K., Nail, C.J., & Keim-Malpass, J. (2017). Survivorship care plans: rural, low-income breast cancer survivor perspectives. *Clinical Journal of Oncology Nursing*, *21*(6), 692-698. doi: 10.1188/17.CJON.692-698.
- Deshields TL, Heiland, ML, Kracen AC, Dua P. (2016). Resilience in adults with cancer:

- development of a conceptual model. *Pscyhooncology*, 25, 11-18. doi: 10.1002/pon.3800.
- Earvolino-Ramirez M. (2007). Resilience: a concept analysis. *Nursing Forum*, 42(2), 73-82. doi:10.1111/j.1744-6198.2007.00070.x.
- Gisiger-Camata, S., Adams, N., Nolan, T. S., & Meneses, K. (2016). Multi-level assessment to reach out to rural breast cancer survivors. *Women's Health (London, England)*, *12*(6), 513–522. Advance online publication. doi:10.1177/1745505716678232.
- Gunn, K.M., Berry, N.M., Meng, X. et al. (2019). Differences in the health, mental health and health promoting behaviors of rural versus urban cancer survivors in australia. Supportive Care Cancer, 1-11. doi: https://doi.org/10.1007/s00520-019-04822-0.
- Heijman W., Hagelaar G., van der Heide M. (2019) Rural Resilience as a New Development

  Concept. In: Dries L., Heijman W., Jongeneel R., Purnhagen K., Wesseler J. (eds) EU

  Bioeconomy Economics and Policies: Volume II. Palgrave Advances in Bioeconomy:

  Economics and Policies. Palgrave Macmillan, Cham.
- Katz, M. L., Reiter, P. L., Corbin, S., de Moor, J. S., Paskett, E. D., & Shapiro, C. L. (2010). Are rural ohio appalachia cancer survivors needs different than urban cancer survivors? *Journal of Cancer Survivorship : Research and Practice*, 4(2), 140–148. doi:10.1007/s11764-010-0115-0.
- López, E. D. S., Eng, E., Randall-David, E., & Robinson, N. (2005). Quality-of-life concerns of African American breast cancer survivors within rural north carolina: blending the techniques of photovoice and grounded theory. *Qualitative Health Research*, *15*(1), 99–115. doi: https://doi.org/10.1177/1049732304270766.
- Livaudais, J. C., Thompson, B., Godina, R., Islas, I., Ibarra, G., & Coronado, G. D. (2010). A

- qualitative investigation of cancer survivorship experiences among rural Hispanics. *Journal of psychosocial oncology*, *28*(4), 361–380. doi:10.1080/07347332.2010.488146.
- McKibbin, C., Lee, A., Steinman, B. A., Carrico, C., Bourassa, K., & Slosser, A. (2016). Health status and social networks as predictors of resilience in older adults residing in rural and remote environments. *Journal of Aging Research*, doi:10.1155/2016/4305894.
- McNulty, J.A., & Nail, L. (2015). Cancer survivorship in rural and urban adults: a descriptive and mixed methods study. *Journal of Rural Health*, *31*(3), 282-291. doi: 10.1111/jrh.12106. Epub 2015 Jan 19.
- Meilleur, A., Subramanian, S. V., Plascak, J. J., Fisher, J. L., Paskett, E. D., & Lamont, E. B. (2013). Rural residence and cancer outcomes in the United States: issues and challenges. Cancer epidemiology, biomarkers & prevention: a publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology, 22(10), 1657–1667. https://doi.org/10.1158/1055-9965.EPI-13-0404.
- Miederma, B., Easley, J.K., & Robinson, L.M. (2013). Comparing urban and rural young adult cancer survivors' experiences: a qualitative study. *Rural Remote Health*, *13*(2), 2324.
- Molina, Y., Yi, J.C., Martinez-Gutierrez, J., Reding, K.W., Yi-Frazier, J.P., & Rosenberg, A.R. (2014). Resilience among patients across the cancer continuum: diverse perspectives. *Clinical Journal of Oncology Nursing 18*(1), 93–101. doi:10.1188/14.CJON.93-101.
- National Cancer Institute. (2012). Psychological stress and cancer.

  Retrieved from https://www.cancer.gov/about-cancer/coping/feelings/stress-fact-sheet.

- Olson, E. A., Mullen, S. P., Rogers, L. Q., Courneya, K. S., Verhulst, S., & McAuley, E. (2014).

  Meeting physical activity guidelines in rural breast cancer survivors. *American journal of health behavior*, 38(6), 890–899. doi:10.5993/ajhb.38.6.11.
- Pascal, J., Johnson, N., Dickson-Swift, V., & Kenny, A., (2014). Returning home: psychosocial care during the re-entry phase of cancer survivorship in rural australia. *European Journal of Cancer Care*, 24(1), 39-49. doi: https://doi.org/10.1111/ecc.12232.
- Reid-Arndt, S. A., & Cox, C. R. (2010). Does rurality affect quality of life following treatment for breast cancer? *The Journal of rural health: official journal of the American Rural Health Association and the National Rural Health Care Association*, 26(4), 402–405. doi:10.1111/j.1748-0361.2010.00295.x,
- Rodgers, B.L., & Knafl, K.A. (1993). Concept development in nursing. 73-92. 2nd ed. Saunders.
- Rogers-Clark, C. (2002). Living with breast cancer: the influence of rurality on women's suffering and resilience. a postmodern feminist inquiry. *Australian Journal of Advanced Nursing*, 20(2), 34-39.
- Rogers, L.Q., Goncalves, L., Martin, M.Y., Pisu, M., Smith, T.L., Hessong, D., Oster, R.A., Qu, H., Shewchuk, R., Iqbal, F., Sheffield, M.E., Minter, A., Baumann, A.A. (2019). Beyond efficacy: a qualitative organizational perspective on key implementation science constructs important to physical activity intervention translation to rural community cancer care sites. *Journal of Cancer Survivorship*, *13*(4), 537-546. doi: 10.1007/s11764-019-00773-x.
- Schiller, C.J. (2018). Teaching concept analysis to graduate nursing students. *Nursing Forum*, 53(2), 248-254. doi:10.1111/nuf.12233.

- Schoenberger, Y. M., Benz, R., McNees, P., & Meneses, K. (2016). Patient-centered outcome evaluation of the rural breast cancer survivors intervention. Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer, 24(4), 1841–1848. doi:10.1007/s00520-015-2974-4.
- Schlegel, R.J., Talley, A.E., Molix, L.A., & Bettencourt, B.A. (2008). Rural breast cancer patients, coping and depressive symptoms: a prospective comparison study.

  \*Psychology and Health, 24(8), 933-948.
- Walker L.O., & Avant K.C. Strategies for Theory Construction in Nursing. (2005). 5th ed. Saddle River, NJ: Pearson Education, Inc.
- Torres, E., Dixon, C. & Richman, A.R. (2016). Understanding the breast cancer experience of survivors: a qualitative study of African American women in rural eastern north Carolina. *J Canc Educ*, 31(1), 198-206. https://doi.org/10.1007/s13187-015-0833-0.
- Walker, L.O, & Avant, K.C. (2005). *Strategies for theory construction in nursing*. 5<sup>th</sup> ed. Saddle River, NJ: Pearson Education, INC.
- Walker, R., Szanton, S.L., & Wenzel, J. (2015). Working toward normalcy post-treatment: a qualitative study of older adult breast and prostate cancer survivors. *Oncology Nursing Forum*, 42(6), 358-367. doi: 10.1188/15.ONF.E358-E367.
- Wells M. Resilience in rural community-dwelling older adults. *J Rural Health*. 2009;25(4):415-419. doi:10.1111/j.1748-0361.2009.00253.x.
- World Bank. (2018). *Rural population (% of total population)*. Retrieved from https://data.worldbank.org/indicator/SP.RUR.TOTL.ZS.
- Zahnd, W.E., Jenkins, W.D., Shackelford, J., Lobb, R., Sanders, J., & Bailey, A. (2018). Rural

cancer screening and faith community nursing in the era of the affordable care act. *Journal of Health Care for the Poor and Underserved, 29*(1), 71-80. doi: 10.1353/hpu.2018.0008.

## Chapter 4

<u>Title:</u> Rural Cancer Survivors' Perceptions of the Nurse-Patient Telemedicine Relationship: A

Multi-Method Study

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#### Abstract

Purpose: To understand rural survivors' experience of participating in a nurse-led telemedicine visit for addressing cancer-related distress.

Participants and Setting: Twenty-five rural-dwelling post-treatment adult head and neck cancer survivors recruited from a cancer center clinic affiliated with an academic health system serving a rural catchment area in the Southeastern U.S.

Methodologic Approach: Multi-method approach using descriptive qualitative interviews and a quantitative survey, the *Telemedicine Satisfaction and Use Questionnaire*.

Findings: Three themes were extracted from the qualitative interviews: rural cancer survivors trust oncology nurses with their distress experience, an oncology nurse telehealth visit increases survivors' access to information and education, and rural cancer survivors overcome technology barriers to speak with an oncology nurse. Quantitative findings indicated high satisfaction with the nurse-patient relationship over telemedicine and lower satisfaction with using telemedicine equipment to connect to a visit.

Implications for Nursing: Rural cancer survivors are willing to overcome technology barriers to discuss cancer-related distress with a nurse over telemedicine. Although they may be willing to be open and vulnerable about distress with an oncology nurse, they are less likely to accept a referral to another provider of psychosocial care. Nurses can incorporate warm handoffs to increase psychosocial referral uptake for rural survivors.

# **Knowledge Translation**

- Rural cancer survivors confronted technology barriers to speak with an oncology nurse over a telemedicine video visit.
- Oncology nurses can establish a trusting therapeutic relationship with rural cancer survivors over a telemedicine video visit, during which survivors will discuss their cancer-related distress.
- Rural cancer survivors with cancer-related distress may be reluctant to be referred to an
  oncology-specialized social worker, but a warm handoff may aid acceptance of this
  transition.

#### Introduction

Rural cancer survivors are 15% more likely to experience distress (psychological, social, spiritual, or physical symptoms impacting survivors' quality of life) than urban survivors (Burris & Andrykowski, 2010). This disparity is due in part to complexities in accessing care when living a long distance from the site of primary cancer treatment. Rural survivors have been known to forgo care due to long travel distances (Lavergne et al., 2011; Pesut et al., 2010). The absence of survivorship care can lead to unaddressed lingering distress due to the permanently life-altering effects of treatment, including persisting side effects such as neuropathy, disfigurement and disability (Ellis et al., 2019).

A telemedicine visit with a nurse has the potential to connect rural cancer survivors with needed care after primary treatment is completed. *Telemedicine* involves the delivery of direct, real-time patient care delivered virtually (ATA, 2020; Doarn et al., 2014), and is a subset of telehealth, which is "the use of electronic information and telecommunications technologies to support and promote long-distance clinical health care, patient and professional health-related education, and public health and health administration (U.S. Department of Health and Human Services, n.d.)."

Telemedicine is conducted synchronously over the phone or a via video visit (VV). A major advantage of a VV is that because the provider can see and hear the patient in real time, they can assess both verbal and non-verbal cues, which makes it particularly amenable to nursing assessment and care needed during the post-treatment survivorship period (DeGuzman et al., 2020).

## **Purpose**

Despite the promise of using telemedicine to deliver rural survivorship care, little is known about how rural patients perceive a nursing telemedicine visit (Hirko et al., 2020; Rouleau et al., 2017). The aim of this study was to understand rural cancer survivors' experience of participating in a telemedicine nurse video visit for addressing cancer-related distress.

#### Methods

## Design

We used a multi-method approach to address the study aim, consisting of qualitative interviews supplemented with secondary analysis of a quantitative survey. Data presented in this paper were collected as part of a larger oncology nurse-led telemedicine intervention study designed to reduce cancer-related distress of rural head and neck cancer survivors (DeGuzman et al., 2020; DeGuzman, Vogel, et al., 2021). All study procedures were approved and overseen by the

#### Sample and Setting

Participants were recruited from a cancer center clinic affiliated with an academic health system serving a rural catchment area in the Southeastern U.S. Adult head and neck cancer survivors who had completed active treatment within the prior 6 months and lived in a rural area defined as living in a county classified by the National Center for Health Statistics as small metro, micropolitan or non-core and traveling at least 45 minutes to reach the cancer center were eligible. Purposive sampling techniques were used to identify participants (Etikan et al., 2016).

#### Intervention

The purpose of the original parent intervention study was to establish feasibility and preliminary efficacy of an oncology-led, distress screening, education, and referral intervention

delivered over a telemedicine VV. During the intervention, one of two oncology-specialized nurses guided participants in the intervention via a HIPPA-compliant telemedicine videoconferencing platform. Thirty participants received the intervention approximately 6 weeks after they completion of treatment. All interventions were conducted between April 2019 and September 2020. Further details regarding the intervention have been previously reported (DeGuzman et al., 2020; DeGuzman, Vogel, et al., 2021).

#### **Data Collection Process**

As the overall purpose of the study was to establish feasible protocols, no data collection was conducted with the first four participants. After the first five participants, we initiated qualitative interviews, leaving 25 participants eligible for qualitative analysis. After the first ten participants, we initiated quantitative data collection, leaving 20 participants available for analysis. **Figure 1** presents the number of participants available for each analysis.

## **Qualitative Data Collection**

Qualitative data were collected from 25 participants through virtual semi-structured interviews and field notes over the same videoconferencing platform (HIPAA-compliant WebEx) used for the intervention. Semi-structured interviews were conducted immediately prior to the intervention and again 6 weeks following the intervention. Interview questions were aimed at capturing participants' perspectives about the nurse-patient relationship experience over a VV, informed by literature about rural cancer survivors' utilization of technology and experiences with virtual access to care (Bernacchi et al., 2021; DeGuzman et al., 2020). At the first interview, we asked participants about typical daily use of technology, goals for the telemedicine appointment, plans for connecting to their telemedicine appointments, and perspectives on developing a relationship with the nurse. During the second interview, we asked

about any challenges they faced during the intervention, and what aspects of the intervention they found helpful. The 25-question guide was iteratively revised during data collection based on the emerging themes. Of note, because data collection spanned the onset of the COVID-19 pandemic, we added two questions to our post-telehealth intervention guide asking about the impact of difficulty accessing supportive care service, given the reduction in in-person services available during the initial months of the pandemic. Examples of interview questions are presented in **Figure 2**.

Interviews were conducted by one of two researchers (V.B. and I.H.). Researchers collected observational field notes during the telemedicine visit, including documenting interactions with those family or friends present. Interviews were audio-recorded with participant permission, then de-identified, transcribed verbatim, and verified using qualitative software NVIVO. Field notes were de-identified and organized chronologically.

## **Qualitative Data Analysis**

We used an inductive, descriptive, qualitative approach to analyze data and reach data saturation (Sandelowski, 2000). One researcher (V.B.) read through the entire data set multiple times to familiarize themselves with the data prior to coding, and memo initial impressions and data patterns, then coded all data.

We utilized process coding and open coding using key phrases and sentences as the unit of analysis. Two researchers (P.D. and V.B.) reviewed the codes, then collapsed them into broader categories, and related categories into themes. After reaching data saturation, we used our interviews with the final five participants to verify our findings (Creswell, 1998).

We used reflexivity, peer debriefing, member-checking and triangulation with all members of the research team (Lincoln & Guba, 1985). The team met weekly to discuss

findings, which were triangulated with observations and interviews. The primary researcher (V.B.) used reflexive journaling and analytic memos and kept an audit trail.

# **Quantitative Data Collection and Analysis**

Immediately following each visit, we administered the 21-item *Telemedicine Satisfaction* and *Use Questionnaire* (TSUQ) to determine their perceptions of the nurse visit. The TSUQ uses a 1-5 scale ranging from strongly disagree to strongly agree. Two domains, *video visits* (VV) and *use and impact* (UI) capture patients' perceptions with using telemedicine the technology (VV) and the usefulness of the technology to impact health (UI). Discriminant validity has been established and internal consistency of the two factors has been shown to be excellent (Cronbach's alpha= 0.96 and 0.92 for VV and UI respectively; Bakken et al., 2006). Data were collected in Qualtrics (Provo, UT), and descriptive statistics were calculated using the Qualtrics *report* function.

#### **Results**

All 25 eligible participants survivors participated in the interviews and 15 of 20 eligible participants completed the TSUQ. **Table 1** depicts their demographic characteristics. Approximately half of the participants in both analyses were female. The majority were non-Hispanic white, and the average participant was 60.5 years old and 60.7 years old in the qualitative and quantitative analyses, respectively.

# **Qualitative Findings**

Three primary themes emerged from the data: 1) rural cancer survivors trust oncology nurses with their distress experience; 2) an oncology nurse telehealth visit increases rural survivors' access to information and education, and 3) rural cancer survivors overcome technology barriers to speak with an oncology nurse.

## Theme #1: Rural Cancer Survivors Trust Oncology Nurses with their Distress Experience

Rural cancer survivors were motivated to speak with an oncology nurse about their cancer distress. When asked what they hoped to get out of the telemedicine visit, many participants said just to talk with the nurse. Participants' primary stated goal for the telemedicine appointment was to discuss their health concerns with the nurse, and several emphasized the value of having a nurse ask questions regarding their health. A 52-year-old male stated his goal going into the appointment was "just getting to talk to him (the nurse) about my concerns." A 33-year female mother of two young children echoed that statement after her appointment, saying the biggest benefit of participating was "just him [the nurse] taking the time to ask me the questions. And you know, identifying with my needs." Furthermore, she stated that "it's good to have someone ask these kinds of questions," referring to questions about her psychosocial well-being, while a 70-year-old male stated, "I appreciate the things you all are looking for," and that he was particularly grateful for questions regarding if he was feeling anxious, depressed, or unable to sleep.

Rural survivors discussed their fears, concerns, and cancer-related distress symptoms with the nurse. For example, a 52-year-old female patient told the nurse that she found the survivorship phase, "overwhelming. I don't feel like I should have to worry all the time!" She expressed relief in being able to discuss her distress with the nurse, telling him that "it's just those same concerns. You know I get this sore throat and it's like, it's just a concern that the cancer may come back like the other time. So it's just a concern that it'll come back like the other two times." A 74-year male participant stated:

"I thought that the nurses I've dealt with have been great. Some of the docs not so much, all the nurses showed compassion. Some of the surgeons, well I know it's a teaching hospital, but I had a lot of surgeries...Anyway the nurses were always compassionate."

Despite participants willingness to speak openly to a nurse about their distress, most were not willing to confide in other members of the healthcare team who were trained in providing psychosocial support. Specifically, 14 participants were offered a referral an oncology-specialized social workers. Over 70% of participants declined this referral. Despite having discussed their distress with the nurse, several explained their cancer-related distress was not severe enough to warrant additional services. For example, a 63-year-old female who had discussed high levels of distress related to the after-effects of cancer treatment declined to speak with a social worker, even as she continued to describe her concerns to the nurse:

"[I don't need to speak to a social worker] at this time. I think I'm doing better. It's this quarantine thing, I've been out of the house twice... And this prothesis... I thought it would be an implant but it's not going to be. [The surgeon] thinks that is not a good idea since we need to check for the cancer."

Similarly, a 54-year-old male seemed comfortable describing his distress to the nurse, but also declined to receive further support from a social worker despite describing difficulties with his appearance resulting from cancer treatment:

"Yeah, I don't go anywhere without my hat on. Look the top of my head was cut off, and on my back and the top of my shoulders...I have a scar from the top of my head to the...I feel freakish. No, no I don't [need a social worker]. The people I socialize with...they are used to it. I wouldn't take my hat off for the longest time...at the restaurants...I used to never go to the restaurants without my hat on because I don't want people to look at me

and be like "oh well what happened to him?" My hair all fell out from radiation. I used to have hair you know. My wife and my grandkids they don't see it. But I do... I know he said [he could refer a social worker], but I know what I'm dealing with. I never asked how successful these surgeries are but I'm alive, so I guess it was successful."

# Theme #2: An Oncology Nurse Telehealth Visit Increases Survivors' Access to Information and Education

During the telemedicine visit, study participants sought information and education from the nurse about the survivorship phase and ways to manage cancer-related distress, including information about healthcare resources they could access in their local communities. A 63-yearold male with a new tracheostomy and oxygen requirement expressed his uncertainty in his ability to keep his business moving forward in the context of his inability to work full time. He told the nurse, "I own my own business, but now...I've been trying to get information on what I can do, on what to do next [to find out about disability]." The nurse guided the participant to his local office of disability for assistance, which field notes revealed that he had been unaware of prior to the visit. We observed the nurses educating participants in ways that assisted their recovery. Two participants experiencing post-operative neck and back pain received teaching about the impact surgery has on muscles and how long to anticipate time to fully recover, and the nurse presented strengthening and stretching exercises designed to increase mobility and comfort. One nurse educated several participants about their lab results and medication side effects and collaborated with the physician to adjust two participants' medication regimens after learning of side effects that were impacting their activities of daily living.

Participants emphasized the importance of having access to the nurse over a telemedicine visit during COVID-19. A 73-year-old female participant experiencing new difficulties with

swallowing stated "yeah it's not easy here [in a rural town] ... I got a referral for a clinic in the city, but everything is kind of on hold right now. It's this quarantine thing! I've been out of the house twice...since they shut it all down." The telemedicine visit allowed her to access nursing education that she might not have otherwise received. During the visit, the nurse discussed soft foods the participant could eat, recommended swallowing exercises, and moved up the participant's follow up appointment.

## Theme #3: Rural Cancer Survivors Overcome Technology Barriers to Speak with an Oncology Nurse

We observed several participants who struggled to connect to the appointment either due to lack of equipment or discomfort using digital technology. For example, a 52-year-old female participant was unable to connect independently to her telemedicine appointment twice, even with the nurse trying to help her via phone. A study team member ultimately drove several hours to her house to help her. When she finally connected, she expressed her distress and frustration at the outset of her appointment, stating: "It was just not connecting! And you know that's just nerve-wracking when something doesn't work and you're trying, you know?"

Despite technology challenges, we observed that participants were committed to overcoming these barriers to speak with the nurse. Some participants sought assistance from either a family member in their home (n=6), and two participants asked their home health care provider to assist with connecting to the appointment. Although many participants had a home-based internet connection, three participants without sufficient broadband travelled to a nearby telehealth satellite site, located at a local clinic or hospital, where a nurse could assist with setting up the equipment. Telehealth satellite sites were also used by participants (n=3) who lacked a

video-capable device to connect to their visit. Participants who used a telehealth satellite site drove an average of 30 minutes to reach the location.

Some participants were limited in their ability to connect, either due to lack of experience with the Internet or difficulties with their broadband signal, sometimes relying on family to help them connect to their appointment. A 74-year-old participant stated: "I don't use technology by choice," explaining that he had relied on his wife to help him use connect. A 52-year-old male participant explained that he asked his son to help him get set up for my telemedicine visit. Others independently persisted through technological barriers to connect with the nurse about their cancer-related distress. Two participants who were unable to maintain a connection to the videoconferencing system ended up switching to a cell phone to continue their conversation with the nurse when their connection couldn't be maintained. Despite experiencing digital challenges, participants were satisfied with their experience connecting to the telehealth appointment. A 70-year-old male tried to connect via his computer, but lost internet connection. He ultimately downloaded the videoconferencing application on his phone and used cellular data to connect. He stated, "I thought it went real well, our internet went out two times today-it's our area wide comcast-so it was hard to figure out how to download the app... I thought this went real well."

## **Quantitative Findings**

Fifteen participants completed the TSUQ. All scores are presented in **Table 2**. The mean scores for each item ranged from 3.00 to 4.47. Overall, participants gave the lowest scores to those questions that asked about use of the technology. For example, the lowest scoring items were "my health is better than it was before I used the technology" ( $\bar{x}$ = 3.00;  $\delta$ =0.97) and "I can always trust the equipment to work" ( $\bar{x}$ = 3.00;  $\delta$ =0.89). All questions related to the nurse interaction were scored the highest of all items, except for two. The highest scoring items were "I

can explain my problems well enough during a video visit" ( $\bar{x}$  =4.47;  $\delta$ =0.50), "my nurse engages me in my care ( $\bar{x}$ =4.33;  $\delta$ =0.60), and "my nurse deals with my problems ( $\bar{x}$ =4.33;  $\delta$ =0.60). Two questions about the nurse interaction received ratings less than 4.0: "talking to a nurse during a video visit is as satisfying as talking in person" ( $\bar{x}$ =3.13;  $\delta$ =1.50) and "video visits make it easier for me to contact the nurse" ( $\bar{x}$ =3.73;  $\delta$ =1.00).

#### **Discussion**

Rural cancer survivors in this study discussed their cancer-related distress with an oncology nurse over telemedicine. Survivors openly discussed specific physical and psychosocial symptoms, despite several stating only a general goal for the visit (e.g., 'to speak with the nurse'), confiding details about their post-treatment fears, challenges, and side effects and exhibiting vulnerability when discussing how distress was impacting their daily lives. These qualitative findings were reflected in the TSUQ survey in which survivors highly rated several aspects of the nurse-patient relationship highly including the ability to explain their problems to the nurse over the telemedicine connection, and their perceptions that the nurse was able to understand their condition, answer questions, deal with their problems, and engage them in their care. To our knowledge, this is the first study to explore the therapeutic nurse-patient relationship between rural cancer survivors and oncology nurses over a telehealth connection and to identify the willingness of rural cancer survivors to connect with an oncology nurse over telemedicine. Given the imbalance between rural cancer survivors experiencing cancer-related distress (about 20%) and the shortage of oncology specialty providers servicing rural areas (Weaver et al., 2013), development of interventions to improve access to rural survivors is paramount. Managing cancer-related distress is well within the scope of oncology nursing

practice (Brant & Wickham, 2013), suggesting that a nurse-led telemedicine intervention in which nurses can foster a therapeutic relationship with patients holds promise for improving access to high quality care for rural cancer survivors. Our findings are consistent with prior research demonstrating that oncology nurses use telemedicine to provide patients an opportunity to discuss their cancer-related distress, and initiate interventions to reduce that distress (Paterson et al., 2020).

Interestingly, all participants in our study openly discussed their cancer-related distress with the oncology nurse, but most of those who were determined to need further psychosocial care declined a referral to the oncology-specialized social worker, commonly stating that they did not need the extra support. Participants' reasons for sharing distress with nurses but not social workers may suggest an inherent trust in the nurse-patient relationship. Trust in the nursing profession is well established; personal characteristics and professional caring behaviors of nurses contribute to a nurse-patient relationship founded on trust (Dinç & Gastmans, 2013). Our study expands on this work by showing that this trusting relationship may extend to virtual visits. Future research should evaluate how trust in the nurse-patient relationship extends to a virtual telemedicine visit. This is particularly salient for rural populations who may not always trust medical providers and may have different expectations for the care and communication they receive from providers (Eaves et al., 2020).

Several participants had trouble connecting to the intervention, although all persisted and were ultimately able to connect by recruiting help from people in their support systems. Some expressed a great deal of frustration at having experienced unsuccessful attempts, while others were more positive about the experience. Difficulties with the technology were reflected in lower scores on the TSUQ data: Participants rated their experience with the technology quite low

relative to other scale measures, as well as compared to other populations (Bakken et al., 2006). Difficulty using technology is a known phenomenon among individuals who do not regularly use the internet (Hall et al., 2015). Their experience reflects the phenomenon of limited *digital inclusion*, which refers to having not only access to equipment, but also the skills to utilize technology (Rhinesmith, 2016). When launching a telemedicine intervention with rural survivors, nurses should bear in mind that rural patients unfamiliar with technology may require additional support to both find a broadband connection, and to utilize unfamiliar technology. Difficulty using technology can ultimately be a barrier to adoption (Campbell et al., 2017), which can further exacerbate rural-urban health inequities if not addressed (Tashkandi et al., 2020). Creating local hubs with equipment and broadband, at community-centered locations such as rural libraries, may be a way to decrease technology barriers for rural cancer survivors (DeGuzman, Jain, et al., 2021).

## **Implications for Oncology Nursing**

Our findings suggest that oncology nurses are well-positioned to lead interventions aimed at addressing cancer-related distress with rural survivors over a virtual connection because of their ability to maintain a trusting therapeutic relationship. One area needing further exploration is understanding how nurses can best engage rural survivors in accepting psychosocial support, when a visit is conducted virtually. Participants in our study exhibited great trust in the nurse but were hesitant to speak with a specialized oncology social worker. A potential way to increase acceptance of further psychosocial care to integrate a *warm handoff* to a social worker or other psychosocial care provider. A warm handoff occurs when the incoming and outgoing healthcare providers exchange real-time information about the plan of care with the patient present (Saag et al, 2018). Within the context of cancer care, when identifying a patient or survivor with high

cancer-related distress, the nurse can introduce the patient to the provider (either in person or virtually). This transition may help combat the abandonment and loss of communication that some survivors feel when treatment ends, particularly for rural survivors (DeGuzman et al., 2017; Rowland et al., 2006). Future research should evaluate the effectiveness of a warm handoff in increasing the uptake of psychosocial care referrals for rural cancer survivors.

#### Limitations

Our sample consisted of rural cancer survivors recruited from one large academic medical center in the mid-Atlantic U.S.; thus, our findings may not be representative of rural cancer survivors from other regions and may not be generalizable to other rural communities. We studied a small sample of head and neck cancer survivors; as such, findings may not reflect the experiences or perspectives of people with other types of cancer. Our study participants were largely non-Hispanic white, which, while reflective of the geographic area from which we recruited participants, and likely does not represent perspectives of rural cancer survivors who come from other racial and ethnic backgrounds. Future research should evaluate impact of a nurse-led telemedicine intervention on patients' cancer-related distress and quality of life using a larger and more diverse rural sample.

## Conclusion

Cancer survivors can benefit from a nurse-led telemedicine visit aimed at identifying and managing cancer-related distress, which may be due to the maintenance of a strong nurse-patient relationship over telemedicine, although patients may not be comfortable receiving psychosocial care from other providers. Further research can help identify strategies for connecting rural survivors with providers who treat cancer-related distress.

### **Chapter 4 References**

#### References

- ATA. (2020). *Telehealth: Defining 21 st Century Care*. 2020. https://www.americantelemed.org/resource/why-telemedicine/
- Bakken, S., Grullon-Figueroa, L., Izquierdo, R., Lee, N. J., Morin, P., Palmas, W., Teresi, J., Weinstock, R. S., Shea, S., Starren, J., & Consortium, Ideat. (2006). Development, validation, and use of English and Spanish versions of the telemedicine satisfaction and usefulness questionnaire. *Journal of the American Medical Informatics Association : JAMIA*, *13*(6), 660–667. https://doi.org/M2146 [pii]
- Bernacchi, V., Zoellner, J., Keim-Malpass, J., & DeGuzman, P. (2021). Rural Resilience in Cancer Survivors: Conceptual Analysis of a Global Phenomenon. *Online Journal of Rural Nursing and Health Care*, 21(1), 159–178.
- Brant, J. M., & Wickham, R. (2013). Statement on the Scope and Standards of Oncology Nursing

  Practice: Generalist and Advanced Practice (J. M. Brandt & R. Wickham, Eds.). Oncology

  Nursing Society.
- Burris, J. L., & Andrykowski, M. (2010). Disparities in mental health between rural and nonrural cancer survivors: a preliminary study. *Psycho-Oncology*, *19*(6), 637–645. https://doi.org/10.1002/pon.1600; 10.1002/pon.1600
- Campbell, J. I., Aturinda, I., Mwesigwa, E., Burns, B., Haberer, J. E., Bangsberg, D. R., Holden, R. J., Ware, N. C., & Siedner, M. J. (2017). The Technology Acceptance Model for Resource-Limited Settings (TAM-RLS): a novel framework for mobile health interventions targeted to low-literacy end-users in resource-limited settings. *AIDS and Behavior*, 21(11), 3129–3140.

- Creswell, J. (1998). Data analysis and representation. Qualitative Inquiry and Research Design.

  Thousand Oaks.
- DeGuzman, P. B., Bernacchi, V., Cupp, C. A., Dunn, B., Ghamandi, B. J. F., Hinton, I. D., Jameson, M. J., Lewandowski, D. L., & Sheffield, C. (2020). Beyond Broadband: Digital Inclusion as a Driver of Inequities in Access to Rural Cancer Care. *Journal of Cancer Survivorship*, 14(5), 643–652. https://doi.org/10.1007/s11764-020-00874-y
- DeGuzman, P. B., Colliton, K., Nail, C. J., & Keim-Malpass, J. (2017). Survivorship Care Plans:

  Rural, Low-Income Breast Cancer Survivor Perspectives. *Clinical Journal of Oncology Nursing*,

  21(6), 692–698. https://doi.org/10.1188/17.CJON.692-698
- DeGuzman, P. B., Jain, N., & Loureiro, C. G. (2021). Public Libraries as Partners in Telemedicine

  Delivery: A Review and Research Agenda. *Public Library Quarterly*, 1–12.

  https://doi.org/10.1080/01616846.2021.1877080
- DeGuzman, P. B., Vogel, D. L., Horton, B., Bernacchi, V., Cupp, C. A., Ghamandi, B. J. F., Hinton, I. D., Sheffield, C., & Jameson, M. J. (2021). Examination of a Distress Screening Intervention for Rural Cancer Survivors Reveals Low Uptake of Psychosocial Referrals. *Journal of Cancer Survivorship*.
- Dinç, L., & Gastmans, C. (2013). Trust in nurse-patient relationships: A literature review. *Nursing Ethics*, 20(5), 501–516. https://doi.org/10.1177/0969733012468463
- Doarn, C. R., Pruitt, S., Jacobs, J., Harris, Y., Bott, D. M., Riley, W., Lamer, C., & Oliver, A. L. (2014). Federal efforts to define and advance telehealth A work in progress. *Telemedicine and E-Health*, 20(5), 409–418. https://doi.org/10.1089/tmj.2013.0336

- Eaves, E. R., Williamson, H. J., Sanderson, K. C., Elwell, K., Trotter II, R. T., & Baldwin, J. A. (2020). Integrating Behavioral and Primary Health Care in Rural Clinics: What Does Culture Have to Do with It? *Journal of Health Care for the Poor and Underserved*, 31(1), 201–217.
- Ellis, M. A., Sterba, K. R., Day, T. A., Marsh, C. H., Maurer, S., Hill, E. G., & Graboyes, E. M. (2019). Body image disturbance in surgically treated head and neck cancer patients: a patient-centered approach. *Otolaryngology–Head and Neck Surgery*, *161*(2), 278–287.
- Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics*, 5(1), 1–4.
- Hall, A. K., Bernhardt, J. M., Dodd, V., & Vollrath, M. W. (2015). The Digital Health Divide:
  Evaluating Online Health Information Access and Use Among Older Adults. *Health Education and Behavior*, 42(2), 202–209. https://doi.org/10.1177/1090198114547815
- Hirko, K. A., Kerver, J. M., Ford, S., Szafranski, C., Beckett, J., Kitchen, C., & Wendling, A. L. (2020). Telehealth in response to the COVID-19 pandemic: Implications for rural health disparities. *Journal of the American Medical Informatics Association*, 27(11), 1816–1818.
- Lavergne, M. R., Johnston, G. M., Gao, J., Dummer, T. J. B., & Rheaume, D. E. (2011). Variation in the use of palliative radiotherapy at end of life: Examining demographic, clinical, health service, and geographic factors in a population-based study. *Palliative Medicine*, 25(2), 101–110. https://doi.org/10.1177/0269216310384900
- Lincoln, Y. S., & Guba, E. G. (1985). Establishing trustworthiness. *Naturalistic Inquiry*, 289, 331.
- Paterson, C., Bacon, R., Dwyer, R., Morrison, K. S., Toohey, K., O'Dea, A., Slade, J., Mortazavi, R., Roberts, C., & Pranavan, G. (2020). The role of telehealth during the COVID-19 pandemic across the interdisciplinary cancer team: implications for practice. *Seminars in Oncology Nursing*, 151090.

- Pesut, B., Robinson, C. A., Bottorff, J. L., Fyles, G., & Broughton, S. (2010). On the road again: patient perspectives on commuting for palliative care. *Palliative and Supportive Care*, 8(02), 187–195. https://doi.org/10.1017/S1478951509990940
- Rhinesmith, C. (2016). Digital Inclusion and Meaningful Broadband Adoption Initiatives Digital Inclusion and Meaningful Broadband Adoption Initiatives.
- Rouleau, G., Gagnon, M.-P., Côté, J., Payne-Gagnon, J., Hudson, E., & Dubois, C.-A. (2017). Impact of information and communication technologies on nursing care: results of an overview of systematic reviews. *Journal of Medical Internet Research*, 19(4), e122.
- Rowland, J. H., Hewitt, M., & Ganz, P. A. (2006). Cancer survivorship: A new challenge in delivering quality cancer care. In *Journal of Clinical Oncology* (Vol. 24, Issue 32, pp. 5101–5104). https://doi.org/10.1200/JCO.2006.09.2700
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334–340.
- Tashkandi, E., Zeeneldin, A., AlAbdulwahab, A., Elemam, O., Elsamany, S., Jastaniah, W., Abdullah, S., Alfayez, M., Jazieh, A. R., & Al-Shamsi, H. O. (2020). Virtual management of patients with cancer during the COVID-19 pandemic: web-based questionnaire study. *Journal of Medical Internet Research*, 22(6), e19691.
- U.S. Department of Health and Human Services. (n.d.). What is telehealth?
- Weaver, K. E., Geiger, A. M., Lu, L., & Case, L. D. (2013). Rural-urban disparities in health status among US cancer survivors. *Cancer*, 119(5), 1050–1057. https://doi.org/10.1002/cncr.27840; 10.1002/cncr.27840

## Figure Legend

Figure 1: Participants eligible for analysis at each stage of data collection of the CARING intervention. CARING= Comprehensive Assistance: Rural Interventions, Nursing and Guidance.

Figure 2: Examples of interview questions asked of participants prior to and following the CARING intervention. CARING= Comprehensive Assistance: Rural Interventions, Nursing and Guidance.

**Table 1: Participant Demographic Characteristics** 

Characteristic	Qualitative Analysis	Quantitative Analysis	
N (%)	(n=25)	(n=15)	
Gender			
Male	14 (56.0%)	7 (50.0%)	
Female	11 (44.0%)	7 (50.0%	
Race			
White	21 (84.0%)	11 (73.3%)	
Other (Black, Asian)	4 (16.0%)	4 (26.7%)	
Hispanic			
Yes	1 (4.0%)	14 (93.3%)	
No	24 (96%)	0 (0%)	
Did not answer	0 (0.0%)	1 (6.7%)	
Age in years (mean, standard	60.52, 14.0, 35-80	60.7, 14.4, 33-88	
deviation, range)			

Table 2: Results of the Telemedicine Satisfaction and Use Questionnaire (n=15)

Field	Mean	Std Deviati on	Minimu m	Maxim um
Video Visits				
A nurse can get a good understanding of my condition during a visit		0.83	2.00	5.00
My nurse answers my questions	4.20	0.83	2.00	5.00
My nurse deals with my problems	4.27	0.57	3.00	5.00
My nurse engages me in my care	4.33	0.60	3.00	5.00
I can explain my problems well enough during a video visit	4.47	0.50	4.00	5.00
The lack of physical contact during a video visit is not a problem	3.53	1.20	1.00	5.00
My privacy is protected during video visits	4.20	0.65	3.00	5.00
Talking to a nurse during a video visit is as satisfying as talking in person	3.13	1.15	1.00	5.00
Video visits make it easier for me to contact the nurse	3.73	1.00	2.00	5.00
Video visits are a convenient form of healthcare for me	3.73	1.18	1.00	5.00
Video visits save me time	3.87	0.96	2.00	5.00
Use and Impact				
I am more involved in my care using the telemedicine system	3.20	0.91	1.00	4.00
The telemedicine equipment is easy to use		0.93	2.00	5.00
The telemedicine system helps me better manage my health and medical needs	3.40	0.80	2.00	5.00
In general, I am satisfied with the telemedicine system	4.00	0.89	2.00	5.00
My health is better than it was before I used the technology	3.00	0.89	1.00	4.00
I follow my doctor's advice better since working with the telemedicine system	3.14	0.74	2.00	4.00
The telemedicine system helps monitor my health condition		0.72	2.00	5.00
It was easy to learn to use the equipment		1.08	2.00	5.00
My doctor uses information from the telemedicine system in my office visits		0.77	1.00	4.00
I can always trust the equipment to work	3.00	0.97	1.00	4.00

Note: participants were asked to rate their response from 1-5, 1 being "strongly disagree" to 5 being "strongly agree".

Figure 1

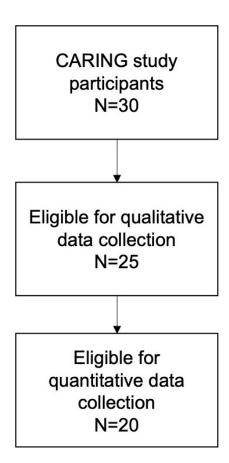


Figure 2

Pre-Intervention Interview	Post-Intervention Interview	
You had your telehealth visit weeks after you finished treatment (we would have to look this up for each pt). did you feel like this visit would have been more helpful if it had come sooner? Or would you have preferred it later?	Is there anything else you would like to tell me about your telemedicine experience?	
Did you feel like one visit with the nurse was sufficient to address any needs you had as a survivor? If not, why? (probe: at what point would additional follow up telehealth visits have been helpful)	[For those who received referrals] after your visit you were referred to a [social worker, speech therapist, etc]. how did you communicate with this person? (probe: If there was an in-person visit, ask about any difficulty traveling to that appointment).	
When you spoke to the nurse during your telehealth visit, you reported experiencing some [fill in: difficulty sleeping, fear, worry, depression, whatever they reported]. We often call this distress. Do you feel that your experience with distress when you were going through treatment was different than distress you experienced once treatment was over?	As someone who used telehealth to get support from a nurse once your main cancer treatment was over, what do you see as the benefits and any potential problems with cancer survivors using telehealth to get this support from a nurse?	

## Chapter 5

## Title

Facilitators and Barriers to Resilience for Rural Cancer Survivors in the Context of COVID-19

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#### Abstract

**Purpose:** To 1) identify the facilitators and barriers of resilience in rural cancer survivors, and 2) identify priority sites to implement future interventions targeting resilience.

**Participants and Setting:** Seven posttreatment rural cancer survivors, four caregivers of rural cancer survivors, and one rural cancer survivor who also identified as a caregiver were recruited from Southwest Virginia.

**Methodologic Approach:** Thematic analysis using line-by-line coding. The inductive development of comparative themes and meanings were guided by the conceptual model of rural resilience.

**Findings:** Three themes emerged from the data: 1) spirituality facilitates resilience in rural cancer survivors, 2) rural cancer survivors accommodate the cultural norms of fatalism, mistrust of providers, and cultural differences to maintain resilience, and 3) rural cancer survivors strengthen resilience through social capital on virtual platforms in the context of COVID-19.

**Implications for Nursing:** Understanding the roles of spirituality, cultural norms, and social capital will help nurses develop and implement interventions strengthening resilience in rural cancer survivors. Nurses can support resilience in rural survivors by incorporating a spiritual assessment into survivorship care, and by guiding survivors to virtual support groups.

## **Knowledge Translation**

- Spirituality facilitates the strengthening of resilience in rural cancer survivors, while rural cultural norms of fatalism, mistrust of local hospitals and cultural differences are barriers to resilience
- Rural survivors are unable to connect with their community networks in-person due to COVID-19, so they are strengthening resilience through social capital on virtual platforms
- Nurses can support resilience in rural cancer survivors by incorporating a spiritual assessment and guiding survivors to virtual support groups

#### Introduction

Nearly 20% of rural cancer survivors experience cancer-related distress (CRD) compared to ~13% of urban survivors (Weaver et al, 2013). Increased levels of CRD lead to poor quality of life (QoL; Hamer et al, 2009). In fact, rural cancer survivors have identified a critical need for interventions that improve their QoL, and for those interventions to be both geographically accessible and culturally relevant (Fuchsia Howard et al, 2014). For example, rural cancer survivors prefer to self-manage CRD using community-based support (Pascal et al, 2015).

One way nurses can support rural survivors' ability to self-manage their CRD is to promote *resilience*, or the ability to make positive adaptations despite adversity, using community-based resources (Cosco, 2017). Cancer survivors with higher resilience have less CRD and improved QoL (Molina, 2014). However, resilience as experienced by rural survivors is poorly understood within the contexts of poor healthcare access and rural community beliefs and values. As a result, there is little evidence to guide the development and implementation of culturally-relevant, geographically-accessible interventions promoting resilience in rural cancer survivors (Bernacchi et al, 2021).

The aims of this study were to 1) identify the facilitators and barriers of resilience in rural cancer survivors, and 2) identify priority sites to implement future interventions targeting resilience. The study was guided by a Bernacchi's conceptual framework (2021) of *rural resilience* that focuses on three domains (spirituality, community networks, and community trust) that have been shown to impact resilience among rural cancer survivors. Attributes of these domains strengthen or reduce resilience (faith, community networks and community trust

increase resilience; fatalism, cultural differences and mistrust of providers decrease resilience; Bernacchi et al, 2021).

#### Methods

## **Setting and Sample**

We recruited post-treatment rural cancer survivors and caregivers of rural cancer survivors from Southwest Virginia. Southwest Virginia encompasses a large region of rural Central Appalachia along the Virginia-Tennessee and Virginia-West Virginia border. This region is geographically isolated with low prevalence of health providers or insurance, and a high prevalence of poverty and poor health outcomes (Synder & Milbrath, 2013). Rural cancer survivors' eligibility criteria included completion of treatment from the participant's first cancer diagnosis, being within 5 years of cancer treatment (this time frame was chosen to allow participants to reflect on the transition to the extended survivorship phases), and residency of an American Community Survey rural defined zip code in Southwest Virginia (Marzorati et al, 2017). Eligibility criteria for caregivers included any family member, friend, or partner who a rural cancer survivor identified are their main source of support and assistance.

Participants were recruited using multiple methods. First, we identified community gatekeepers from the Southwest Virginia Community Advisory Board (CAB), which is associated with the Cancer Center, and includes survivors, healthcare professionals, and caregivers of cancer survivors from across Southwest Virginia. These CAB members posted recruitment flyers in their local community clinics and churches. Study flyers were also shared through a cancer support group in Central Virginia, a Central Virginia church group, and the Virginia Rural Health Association Board. Finally, study participants were asked to share study eligibility information with their personal contacts.

Rural cancer survivors and caregivers who responded and met eligibility criteria provided written consent via email, or verbal consent over telephone, in accordance with approved IRB procedures.

#### **Data Collection**

Participants chose if they would like to conduct their interview in-person, by telephone, or by videoconferencing via Zoom. Participants received a \$50 gift card after completing their interview. Demographics, including age, race and ethnicity, cancer diagnosis, and types of cancer treatment undertaken (survivors), were collected during the interview.

Data collection occurred from semi-structured participant interviews. Two interview guides were developed, one for survivors, and one for caregivers (**Table 1**). Interview questions were developed based on the attributes of the conceptual framework. Interviews were conducted via telephone or Zoom and ranged from 45-90 minutes. Interviews were audio recorded, deidentified, and transcribed verbatim. All transcripts were imported into Dedoose, a qualitative analysis software (Dedoose, 2021).

## **Data Analysis**

Sampling, data collection and data analysis occurred concurrently and iteratively until the point of meaning saturation (Boddy, 2016; Hennick et al, 2017). Initial coding strategies relied on an inductive approach using open and in vivo coding to capture barriers and facilitators to rural resilience not identified in the conceptual framework. A second, a priori coding strategy based on the attributes and domains (social capital, faith, cultural norms) of the conceptual framework was applied to the entire data set, followed by inductive theme development through thematic analysis (Sandeloweski, 2000; Braun & Clarke, 2008). A codebook containing the code name, description, code frequency in each data set, and exemplars was maintained.

All text data were analyzed by (a) constant immersion in the data throughout the analytic process, in which the first author read each transcript several times during each step of analysis, (b) a line-by-line analysis in which first the inductive coding strategies, and then the deductive theoretical coding strategy, were applied to the entire data set, (c) codes were grouped together to form inductive themes using thematic analysis (Braun & Clarke, 2008). To establish trustworthiness, dependability, credibility, and transferability, the first author kept a reflective journal, including reflection on prior assumptions and beliefs about the research, as emotional responses to participants' narratives. Additional strategies to establish rigor include (a) a thorough audit trail of decisions made, and (b) opening all aspects of the design for review by the research team, (c) regular peer debriefing sessions of the first author with rural cancer survivor experts (PD & KP), and d) contextual review of the results (Lincoln & Guba, 1985; Morse, 2015).

## **Findings**

#### Sample

Six rural cancer survivors (S-1 to S-6), four caregivers (C-1 to C-4), and one rural cancer survivor who was also a caregiver for another rural survivor (SC-1) were screened and met eligibility criteria. All participants declined an in-person interview due to COVID-19 precautions, and all participants identified as female. Four participants elected to have their interview via zoom (C-1, C-3, C-4, S-7), and seven participants chose to interview via telephone due to lack of broadband connection (SC-1, S-4), lack of a video capable device (S-1), or lack of comfort using videoconferencing technology (S-2, S-3, S-5, S-6). Two participants joined their zoom interview from work because their home broadband was poor (S-5, C-3). Interviews occurred between October 2021 and January 2022. Characteristics of the individual participants are presented in **Table 2**.

#### **Themes**

Rich narratives reflected the personal experiences of rural cancer survivors as the transition into survivorship impacted their resilience within the context of a pandemic. Three themes emerged: 1) spirituality facilitates resilience in rural cancer survivors, 2) rural cancer survivors accommodate the cultural norms of fatalism, mistrust of providers, and cultural differences to maintain resilience, and 3) rural cancer survivors strengthen resilience through social capital on virtual platforms in the context of COVID-19. Illustrative quotes of each theme, in addition to those provided below, are presented in **Figure 1**.

#### Theme 1: Spirituality facilitates resilience for rural cancer survivors

Rural cancer survivors described the integral role of spirituality in strengthening their resilience. Caregivers of rural survivors described faith as their care recipient's source of resilience. C-1 explained "In my mom's case, her faith *is* her resilience...my mother's faith takes

her through just about everything." C-2 stated that for her father, resilience is "Just not giving up. And hope. And faith."

Survivors described their faith in God as critical to strengthening resilience. Survivors discussed trusting God to help them through cancer-related challenges. S-4 explained:

"You walk this journey not by sight, but by faith. And it builds character, going through this journey. God has brought you to it, he will bring you through it. And that's every single day...it will help you to stay resilient through it all, and it will help your faith walk, which is just that this journey is not by sight, but by faith...it's the same step. You can't walk your faith-walk without also understanding that you've gotta be resilient."

When asked about the role of spirituality in resilience, S-3 stated:

"Well, you're always going to have trials in your life...I've always had a strong faith...
even when I wasn't doing what I know I should have been doing, I always knew that God
wasn't going to forsake me."

Survivors reported turning to faith to strengthen their resilience when their resilience was weakest. Survivors discussed turning to their faith because they could depend on God as a constant and consistent source of support. When asked what she did to strengthen her resilience, S-2 shared:

"I am a religious person. And I really, I just turned to my faith...God reaches out in many ways if we're open to it, if we listen...you just have to be willing to listen, and not be afraid to act...He speaks to all of us, it's the degree to which we are willing to listen. And that's what makes a difference, in many cases, where people are resilient...faith is moving forward, even when you don't know if you can."

S-1 also discussed turning to God in moments of weak resilience during her cancer journey:

"I can call God anytime of day or night or whatever, and he is there. Giving me that inner peace that I need...God, he gives me that inner peace. He lets me know, daughter, I am here and there is nothing that is too difficult for me to do in your case. And no matter what it is, I have you in the palm of my hand. You just have to trust me, you just have to believe that I will do whatever I promise will be done."

Overall, ten participants described the importance of spirituality to their resilience. However, C-3 explained that her mother was "very closed in her spirituality," and stated "I don't even know if she was very spiritual" when asked if spirituality had a role in her mother's cancer journey.

# Theme 2: Rural cancer survivors accommodate cultural norms of *fatalism*, *mistrust of local hospitals*, and *cultural differences* to maintain their resilience

Rural survivors identified cultural norms as barriers to resilience that impacted the health-seeking behaviors rural cancer survivors made. For example, rural cancer survivors reported keeping their cancer diagnosis and journey private due to high levels of community fatalism towards cancer. S-6 described her decision not to tell her community about her cancer journey because "they think that you're gonna die." C-3 described her community's cancer beliefs, which impacted her mother's decision when telling people about her cancer journey:

"I feel like it's resignation. It's immediate acceptance. It's not always sad, but it's not oh, I'm going to fight this. I'm going to get through it. It's oh, this is what it is, so I'm just going to deal with it. But in a less motivated, less resilient way...again, I think it's that learned helplessness."

SC-1 shared how fatalism impacted her choice to share her cancer journey only with close family and friends:

"When I was diagnosed I feel like it was very frightening. And the way that people deal with death in this area and cancer too-it may be more frightening here than in a city where you have more information and stuff like that...it's just more frightening."

Survivors discussed a community belief that local hospitals are unable to provide quality care due to lack of resources. S-3 explained that mistrust in local hospitals has been a part of her community's culture for generations:

Cultural norms also influenced rural cancer survivors' health-seeking behaviors.

"Well, I guess from previous experience, or previous family members' experience. And I do think it's a generational thing. My mother had her surgeon at the major academic hospital. It's just, in this area, you know that if you have a major illness, you're not going to stay here."

S-7 explained her community's mistrust in local hospitals impacted her decision to seek care from an academic hospital:

"I'm not trying to blame anybody. I think they're doing the best with what they've got.

They're not a University Health system...But given that they are a stand alone rural health system I'll give them a pass. It's not as bad as it was when I first moved here when people would say "don't go to the local hospital or you'll die." It's not as bad as that all the time.

Not all the time. Honestly, all the time you heard that, and it was true. It was crazy. I can say I've lived here long enough that that was true."

Rural survivors reported lowering their expectations for cultural sensitivity from healthcare providers to maintain their resilience. For example, six survivors and three caregivers reported they wanted spirituality to be incorporated into cancer care. When asked if her healthcare team ever brought up the role of spirituality in her cancer journey, S-3 said:

"No, no. Not until my second biopsy when the doctor said something to me, and I said I'm going to be OK if I have to do it or if I don't have to do it. I'm going to be OK either way. And I realized that he knew what I meant. But, no one ever said anything to me about religion through any of it."

S-3 stated she would have appreciated a spiritual assessment. However, she and other survivors didn't expect healthcare providers to perform a spiritual assessment, because spirituality is not a part of current health culture. S-2 explained:

"I think there are a lot of facilities, usually in larger cities, where people look down on the spiritual because they're afraid of being considered ignorant. Or, the scientific community, it's hard sometimes to acknowledge the science and the scientific part of it while also acknowledging the spiritual."

Black rural survivors reported accommodating cultural differences and biases in the healthcare setting. S-4 explained the challenge of interacting with her predominantly white healthcare team:

"The expectancy is that you come in, and you *blend* in. *That's* the expectancy. And you have to be a strong, resilient person to incorporate your own culture into things....I just think, as African Americans we are a small part of the [rural] population and people just expect that you will comply to what they comply to. And you do."

# Theme 3: Rural cancer survivors report strengthening resilience through social capital on virtual platforms within the context of COVID-19

Rural cancer survivors discussed the role of social capital and cohesion within their communities in facilitating resilience. SC-1 shared, "I think that rural communities really help people get through things better. I've lived in cities too, that's something that I felt attracted me to the small-town life." S-2 shared:

"I believe in the value of being in a rural community...in a rural community, word passes quickly when someone has a major illness and people begin to reach out and do small things or raise money or let them know they are praying or take food to the family or just do things for that person and let them know they are not alone. I think that makes a huge difference."

However, due to the impact of COVID-19, rural survivors have been unable to travel to local sites to connect with their community networks in-person. C-4 described the isolation for her and her father:

"We went straight [to the hospital] and back and we didn't go anywhere in between....At the moment I'm just kind of staying around the house. I need to...I'm afraid to go out and get COVID."

S-7 discussed the negative impact COVID-19 isolation had on her resilience since she couldn't connect to her community networks at work:

"So my resilience was at its weakest through all of 19 and early 2020. Especially when they sent me home from work, that was awful! Because I'm just at home working and I can't see my coworkers and I can't talk to my clients about anything."

Since survivors were unable to connect with community networks in-person, they sought social support through virtual platforms. Survivors used telephone prayer chains, apps, and chat-based social media groups. For example, S-2 used a prayer chain group to connect with her church:

"My church and I text each other all the time... we communicate all the time though a group text, and people minister to one another. You don't have to be in someone's

presence to communicate with them and through them and to feel God's love through them."

S-7 used a phone app to join a support group and strengthen her resilience through social networks.

"The support you get from these people is unbelievable. Like if someone who used to be real active suddenly isn't then people will be like "hey where are you at?" It's amazing how encouraging they are. And that's what everyone needs...whether it's your friends or your neighbors or your church...we are social beings and we need that."

C-4 described using a social media group to help support her father:

"What they had on social media...a prayer chain and stuff. He couldn't see that. He was blind. But he knew about it. We told him, and we read it all...and that's one good thing until we get back in church, you know?"

When asked about the role social media groups had in strengthening resilience, SC-1 explained: 
"It's for people who have bladder cancer or people who are caregivers for someone with bladder cancer and people can just post whatever and it's really helpful for people...I mean really everyone says everything especially on the page. I mean people really do just say anything...and people are just like that's ok, we are here for you."

#### **Discussion**

Rural cancer survivors in this study described both facilitators and barriers of rural resilience based on the conceptual model of *rural resilience*. Rural cancer survivors identified spirituality as a critical facilitator of resilience, and maintained resilience by adjusting their health-seeking behaviors to avoid the barriers of rural cultural norms (fatalism, mistrust of local hospitals, cultural differences).

Rural cancer survivors utilize spirituality to strengthen resilience. Previous studies have identified a positive correlation between spirituality and resilience (Schwalm et al, 2021), which has improved patient outcomes. Rural cancer patients have also used faith to manage CRD (Yeung et al, 2022). For example, among breast cancer survivors, faith improves survivors' health outcomes (Meraviglia, 2006). Furthermore, rural patients have reported wanting spirituality to be incorporated into their healthcare (Fuchs et al, 2021). Within the healthcare setting, cancer patients' QoL increases when clinicians incorporate spiritual needs (Kamijo & Mijaymura, 2020). However, clinicians may undervalue the importance of spirituality to patients' cancer journeys and health behaviors (Kelly et al, 2022), and clinicians rarely incorporate spirituality into healthcare (Peteet & Balboni, 2013). Unmet spiritual needs result in increased levels of CRD, which reduce QoL (Kelly et al, 2022). As our participants explained, clinicians may find it challenging to incorporate spirituality into cancer care because it will be viewed as unscientific. Future research should investigate healthcare providers' perceptions of barriers and facilitators to incorporating spirituality into cancer care.

Rural survivors identified cultural norms of *fatalism*, *mistrust of local hospitals* and *cultural differences* as barriers to resilience that impacted their health-seeking behaviors. Rural communities are more likely to believe that cancer is always fatal (Jensen et al, 2022). Fatalism is known to impact rural residents' decisions to decline preventative cancer screenings (Crosby & Collins, 2017), and may impact rural cancer patients' decisions to seek treatment (Farmer et al, 2012). Clinician may perceive rural culture a barrier to providing care because rural values and beliefs differ from those of the healthcare system (Farmer et al, 2022).

Participants described low levels of trust for their *local* healthcare systems due to lack of resources. This finding varies from previous studies, in which rural residents have reported

greater trust in community-based providers for healthcare (Myrick & Hendryx, 2021). However, this finding must be contextualized within recent rural hospital closures and pandemic. While rural hospitals often perform equally to urban once in terms of morbidity and mortality rates (Greenwood-Eriksen et al, 2021), rural hospitals are vulnerable to poor finances, outdated facilities, closures (Diaz & Pawlik, 2020), and lack of healthcare staff due to the strain of COVID-19 (Cheek et al, 2021), all of which may impact the community's perception of local facilities and what services their providers can safely offer. Future research should investigate the impact of the pandemic and hospital closures on rural survivors' health-seeking behaviors.

Cultural differences and biases are significant barriers for Black rural cancer survivors. In the healthcare setting, racial bias and discrimination decrease resilience, increase CRD, and decrease QoL for cancer survivors (Bernacchi et al, 2021). Rural populations and culture are predominantly White (Farmer et al, 2012), with about 8% being Black and 9% being Hispanic (Zahnd et al, 2021). However, rural Black residents have a greater cancer burden compared to rural White residents (Zahnd et al, 2021), so research is critically needed to address intersectionality of rural and race and inform culturally-appropriate care for Black rural survivors (Farmer et al, 2012).

A secondary aim of this study was to explore locations rural cancer survivor travelled to in order to strengthen resilience. We found rural cancer survivors are not traveling to connect with facilitators of resilience in-person due to COVID-19. Instead, they are strengthening resilience through social capital in virtual platforms. The utilization of virtual platforms for social support and mental healthcare has increased rapidly due to COVID-19 (Akhther & Sopory, 2022). Seeking peer support for health issues through social media platforms may improve mental health, and can increase health-seeking behaviors (Naslund et al, 2016). Future

research should investigate changes in measurable outcomes (CRD, QoL) of cancer survivors utilizing virtual platforms to strengthen resilience.

#### Limitations

Several limitations must be addressed in this study. Our findings may not be transferable to various rural populations due to the study's qualitative and descriptive nature, and the small sample size. Additionally, only female survivors and caregivers were recruited, and our findings may reflect characteristics of rural women navigating cancer in Southwest Virginia. Finally, due to the nature of cancer treatment, participants were immunocompromised and unable to complete their interview in-person. Even so, this study included in-depth, participant-centered narratives from both rural survivors and caregivers in as they adjusted to survivorship within the context of a pandemic.

#### Conclusion

Our findings provide critical descriptive evidence that spirituality facilitates resilience for rural cancer survivors, and that rural cultural norms influence survivors' health decisions. In the context of COVID, rural survivors prioritize virtual support groups to strengthen resilience.

Clinicians should incorporate a spiritual assessment into survivorship care, and guide survivors to virtual support groups.

## **Implications for Practice**

Nurses can support resilience in rural survivors by including a spiritual assessment into survivorship care. Spirituality increases QoL in cancer survivors, while unmet spiritual needs increase CRD (Gudenkauf et al, 2019; Peteet & Balboni, 2013). Integrating spirituality into healthcare may improve patient-centered care, patient outcomes, and support patients' decision-

making processes (Fuchs et al, 2021). Nurses should advocate for spiritual assessments and offer to incorporate spiritual interventions (ex: pray with a patient before surgery).

In addition, nurses should identify existing virtual support groups, and guide rural survivors towards them to strengthen resilience. Nurses could have a list of virtual support groups on various to give to rural survivors. If rural survivors face barriers to accessing virtual platforms, such as poor broadband, nurses can suggest accessing chat-based virtual platforms (ex: Facebook) at community-based locations, such as local libraries (DeGuzman et al, 2020).

## **Chapter 5 References**

#### References

- Boddy, C. R. (2016). Sample size for qualitative research. *Qualitative market research: an international journal*, 19(4), 426-432. Doi.org/10.1101/QMR-06-2016-0053
- Bernacchi, V., Zoellner, J., DeGuzman, P. (2021). Rural resilience in cancer survivors: conceptual analysis of a global phenomena. *Online Journal of Rural Nursing and Health Care*, 21(1). https://doi.org/10.14574/ojrnhc.v21i1.676.
- Braun, V., & Clarke, V. (2008). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101. http://dx.doi.org/10.1191/1478088706qp063oa.
- Cheek, C., Elmer, H., Anderson, T., Baxter, T., & Wooler, M. (2021). Decommissioning and recommissioning a regional hospital in response to a COVID-19 outbreak. *Rural and remote health*, 21(2), 6256. https://doi.org/10.22605/RRH6256
- Cosco, T. D., Kaushal, A., Hardy, R., Richards, M., Kuh, D., & Stafford, M. (2017).

  Operationalising resilience in longitudinal studies: a systematic review of methodological approaches. *Journal of epidemiology and community health*, 71(1), 98–104.

  https://doi.org/10.1136/jech-2015-206980
- Dedoose Version **9.0.17**, web application for managing, analyzing, and presenting qualitative and mixed method research data **(2021)**. Los Angeles, CA: SocioCultural Research Consultants, LLC <u>www.dedoose.com</u>.
- DeGuzman, P. B., Bernacchi, V., Cupp, C. A., Dunn, B., Ghamandi, B., Hinton, I. D., Jameson, M. J., Lewandowski, D. L., & Sheffield, C. (2020). Beyond broadband: digital inclusion as a driver of inequities in access to rural cancer care. *Journal of cancer survivorship:*research and practice, 14(5), 643–652. https://doi.org/10.1007/s11764-020-00874-y

- Farmer, J., Bourke, L., Taylor, J., Marley, J. V., Reid, J., Bracksley, S., & Johnson, N. (2012).

  Culture and rural health. *The Australian journal of rural health*, 20(5), 243–247.

  https://doi.org/10.1111/j.1440-1584.2012.01304.x
- Fuchs, J. R., Fuchs, J. W., Hauser, J. M., & Coors, M. E. (2021). Patient desire for spiritual assessment is unmet in urban and rural primary care settings. *BMC health services* research, 21(1), 289. https://doi.org/10.1186/s12913-021-06300-y
- Fuchsia Howard, A., Smillie, K., Turnbull, K., Zirul, C., Munroe, D., Ward, A., Tobin, P., Kazanjian, A., & Olson, R. (2014). Access to medical and supportive care for rural and remote cancer survivors in northern British Columbia. *The Journal of rural health :*official journal of the American Rural Health Association and the National Rural Health Care Association, 30(3), 311–321. https://doi.org/10.1111/jrh.12064
- Gudenkauf, L. M., Clark, M. M., Novotny, P. J., Piderman, K. M., Ehlers, S. L., Patten, C. A., Nes, L. S., Ruddy, K. J., Sloan, J. A., & Yang, P. (2019). Spirituality and Emotional Distress Among Lung Cancer Survivors. *Clinical lung cancer*, 20(6), e661–e666. https://doi.org/10.1016/j.cllc.2019.06.015
- Hamer, M., Chida, Y., & Molloy, G. J. (2009). Psychological distress and cancer mortality. *Journal of psychosomatic research*, *66*(3), 255–258. https://doi.org/10.1016/j.jpsychores.2008.11.002
- Hennink, M. M., Kaiser, B. N., & Marconi, V. C. (2017). Code Saturation Versus Meaning Saturation: How Many Interviews Are Enough?. *Qualitative health research*, 27(4), 591–608. <a href="https://doi.org/10.1177/1049732316665344">https://doi.org/10.1177/1049732316665344</a>
- Lincoln, Y. S., & Guba, E. G. (1985). Establishing trustworthiness. *Naturalistic Inquiry*, 289, 331.

- Marzorati, C., Riva, S., & Pravettoni, G. (2017). Who Is a Cancer Survivor? A Systematic Review of Published Definitions. *Journal of cancer education : the official journal of the American Association for Cancer Education*, 32(2), 228–237. https://doi.org/10.1007/s13187-016-0997-2
- McKibbin, C., Lee, A., Steinman, B. A., Carrico, C., Bourassa, K., & Slosser, A. (2016). Health Status and Social Networks as Predictors of Resilience in Older Adults Residing in Rural and Remote Environments. *Journal of aging research*, 2016, 4305894. https://doi.org/10.1155/2016/4305894
- Molina, Y., Yi, J. C., Martinez-Gutierrez, J., Reding, K. W., Yi-Frazier, J. P., & Rosenberg, A.
   R. (2014). Resilience among patients across the cancer continuum: diverse
   perspectives. *Clinical journal of oncology nursing*, 18(1), 93–101.
   https://doi.org/10.1188/14.CJON.93-101
- Morse J. M. (2015). Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry. *Qualitative health research*, 25(9), 1212–1222. https://doi.org/10.1177/1049732315588501
- Myrick, J. G., & Hendryx, M. (2021). Health information source use and trust among a vulnerable rural disparities population. *The Journal of rural health: official journal of the American Rural Health Association and the National Rural Health Care Association*, 37(3), 537–544. <a href="https://doi.org/10.1111/jrh.12561">https://doi.org/10.1111/jrh.12561</a>
- Pascal, J., Johnson, N., Dickson-Swift, V., & Kenny, A. (2015). Returning home: psychosocial care during the re-entry phase of cancer survivorship in rural Australia. *European journal of cancer care*, 24(1), 39–49. https://doi.org/10.1111/ecc.12232
- Sandelowski M. (2000). Whatever happened to qualitative description?. Research in nursing &

- health, 23(4), 334–340. https://doi.org/10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g
- Snyder, A. E., & Milbrath, G. R. (2013). Description of healthcare needs at an episodic clinic in rural southwest Virginia. *Rural and remote health*, *13*(4), 2557.
- Schwalm, F. D., Zandavalli, R. B., de Castro Filho, E. D., & Lucchetti, G. (2021). Is there a relationship between spirituality/religiosity and resilience? A systematic review and meta-analysis of observational studies. *Journal of health psychology*, 1359105320984537. Advance online publication. https://doi.org/10.1177/1359105320984537
- Weaver, K. E., Geiger, A. M., Lu, L., & Case, L. D. (2013). Rural-urban disparities in health status among US cancer survivors. *Cancer*, 119(5), 1050–1057. https://doi.org/10.1002/cncr.27840
- Zahnd, W., & Jenkins, W. D. (2018). Rural Women's Perceptions About Cancer Disparities and Contributing Factors: a Call to Communication. *Journal of cancer education : the official journal of the American Association for Cancer Education*, 33(4), 749–756. https://doi.org/10.1007/s13187-017-1196-5

# Figure Legend

Figure 2: Themes and exemplar quotes

Table 1. Examples of Interview Questions for Rural Cancer Survivors and Their Caregivers Based on Attributes of the Rural Resilience Conceptual Framework

Attribute from the Conceptual Framework that Developed the Questions	Interview Questions for Cancer Survivor	Interview Questions for Caregivers of Cancer Survivor
Community Networks	Can you tell me about a time when your community networks helped you feel supported after your treatment?	Who do you think has helped your loved one to adapt to being a cancer survivor?
Faith	Please tell me about the role, if any, that spirituality has in your post-treatment care.	Can you tell me about the places you and your loved one go to in order to feel faith?
Fatalism	What is the first thought that people in your community have when they hear "cancer?" Why?	What do you think the attitude your community has towards cancer is? Why?
Provider Mistrust	Can you tell me about the support you've gotten from your healthcare team as a survivor?	Can you tell me about your relationship with your loved one's healthcare team?
<b>Community Differences</b>	What is unique about resilience in your community?	How can healthcare providers do a better job supporting rural cancer survivors to strengthen resilience?
Trust in Community	Are there any activities you participate in to strengthen your resilience? Why (those activities)?	Can you tell me about where you and your loved one go to in order to feel a sense of community trust?

Table 2. Participant demographic characteristics of survivors and caregivers

Participant	Status	Age (years)	Race	Survivor's cancer diagnosis	Care recipient's cancer diagnosis	Survivor's treatments
S-1	Survivor	82	Black	Breast		C, R, S
S-2	Survivor	65	White	Breast		C, R, S
S-3	Survivor	60	White	Breast		R, S
S-4	Survivor	68	Black	Colon		S
S-5	Survivor	57	White	Gynecologic		C, S
S-6	Survivor	67	White	Breast		R, S
SC-1	Survivor & Caregiver	46	White	Bladder	Lymphoma	S
<b>C-1</b>	Caregiver	60	N/A		Prostate	C, R, S
C-2	Caregiver	26	White		Head and Neck	C, R
C-3	Caregiver	53	White		Lymphoma	S
C-4	Caregiver	49	White		Bladder	R & S

Note. C indicates chemotherapy, R indicates radiation, and S indicates surgery

Figure 1

Theme 1:	Spiritua	lity fac	ilitates
resilience	in rural	cancer	survivors

And you've been around all these years, and I think God didn't put you here for nothing and I just keep on keeping on. (S-1)

Faith is moving forward, even when you don't know if you can...I've always known that He cared about every aspect of your life every day and I truly believe descriptions that says that all things work together for them that love...and He uses it and He uses everything that can happen either-IF we allow Him to. (S-2)

It's the same step. You can't do one without the other. You can't walk your faith walk without understanding that you've got to be resilient. (S-4)

[Spirituality] definitely has [strengthened his resilience]. We didn't really go the church or anything before all of this happened. I don't wanna say that it wasn't really his thing, because he always believed God and stuff like that, but it's like when he got diagnosed it's like that's what opened his eyes to say, there is more out there. And he's just been a different person since then. (*C-3*)

# Theme 2: Rural cancer survivors accommodate cultural norms of fatalism, mistrust of local hospitals, and cultural differences to maintain their resilience

Yeah, [my community sees cancer as] like a monster. It's kind of like squid game. (*C-3*)

I wasn't [telling anyone about my cancer] at first, I didn't-I thought I could do this with just family and friends. To see how the diagnosis would be...anytime you hear stories, there's just this fear. (S-4)

And you know, years and years ago, yes, cancer was a death sentence. But it's not now. If you take care, once again, and do what you have to do. (S-3)

When you hear oh that she has cancer, and everybody immediately thinks, oh well she's gonna die. Why is that? But most people think that. Some people do survive! (S-1)

Theme 3: Rural cancer survivors report strengthening resilience through social capital on virtual platforms within the context of COVID-19

I have not been able to get back to church, and COVID has had a lot to do with that...I have four prayer chains on my phone. Four prayer chains from different churches and I am constantly on the phone and you know, praying with somebody or for some need...Did you hear that? My son just walked in and said my neighbor is in the hospital and said mama, you need to pray. We were talking about my praying and outreach to the community. Now later on tonight, I'll get 2-3 phone calls saying, "did you hear? We need to pray." Now it's my faith and I gotta keep up whether I get a phone call or not because we gotta go to Him in his Son's name and whatever we ask, it gets done. (S-1)

I don't think that there was any [support from the healthcare team]. I've gotten most of my support through Facebook groups...for bladder cancer and for my mom's cancer.

When I first got the bladder cancer I like to responding, I liked when young people would respond, because I was really young so I would like to respond to people and talk about my age, you know, where I live and what they found and stuff. And with my mom I don't think I asked many questions I just kind of followed it. And I invited my mom to, to both of these groups and we would talk about it. Like people would make jokes on the group for bladder cancer and we would talk to each other and be like oh, did you see this today? (SC-1)

So I have been able to stay connected period now, my church hasn't had church. We have been very different, we haven't really gotten back to church...but we communicate all the time through a group text, and people minister to one another. (S-2)

# Chapter 6

#### Conclusion

# **Summary of dissertation findings**

This dissertation has provided a comprehensive understanding of resilience in rural cancer survivors within the rural geographic and cultural contexts. To understand resilience in the rural cultural context, I have identified the concept of *rural resilience* within the global literature and developed an evidence-based conceptual framework for rural resilience based on three cultural domains: spirituality, social capital, and cultural norms (Chapter 3). Within these domains, I identified impacts of resilience: faith, community networks and community trust strengthen resilience, while fatalism, cultural differences, and provider mistrust weaken resilience. I also identified the relationship of rural resilience to CRD and QoL. Chapters 4 and 5 build on this conceptual framework of rural resilience by examining a geographically-accessible intervention that addresses CRD (Chapter 4), and providing an in-depth understanding of cultural barriers and facilitators to resilience (Chapter 5).

In Chapter 4, I discuss rural survivors' experiences using a nurse-led videoconferencing intervention to address their CRD. Rural survivors face challenges accessing telehealth due to poor broadband, lack of a video-capable device, or lack of comfort using technology. However, rural survivors illicit help to virtually connect to the nurse through family, community healthcare providers, and local telehealth sites. Rural survivors prioritize speaking with the nurse about their CRD through videoconferencing. Survivors also express comfort being vulnerable with the nurse, and thus benefit from a therapeutic nurse-patient relationship on a virtual platform.

In Chapter 5, I provide rich description of the facilitators and barriers to resilience in rural cancer survivors, guided by the cultural domains of the conceptual framework. Contrary to the

conceptual framework, rural survivors discuss trusting distant oncology-specialized healthcare providers, but not trusting their *local institutions* due to poor resources. Rural cancer survivors identify spirituality as a critical facilitator of resilience, while the cultural norms of fatalism, cultural differences, and mistrust of local hospitals are barriers to resilience. Rural cancer survivors also discuss strengthening their resilience through social capital, through virtual platforms in the context of COVID-19. In the context of COVID-19, survivors report seeking social support through virtual platforms such as social media groups, support groups through phone apps, texting and telephone prayer chains.

# Changes made in Chapter 5 from the dissertation proposal (Chapter 2)

Due to COVID-19, I had to adjust the methods to ensure safety of participants. I had originally planned to conduct an ethnographic study with prolonged field immersion for data collection. However, rural cancer survivors and caregivers were not willing to meet in-person in the context of COVID-19. Instead of ethnography, I used descriptive qualitative methods, which are appropriate for answering the questions of the study, but allow for virtual data collection of sensitive topics (Mealer & Jones, 2014).

I adjusted data analysis based on the study findings. I originally planned to conduct a geospatial analysis of community sites rural cancer survivors travelled to in order to strengthen resilience. However, I found that immunocompromised rural survivors have been isolated from community networks such as their church groups, due to the pandemic. Instead, they sought support from virtual, chat-based platforms. Based on this finding, geospatial analysis was inappropriate. Instead, I identified the virtual platforms rural survivors reported using in their semi-structured interviews.

In the dissertation proposal, I had originally planned to recruit between 20-30 rural cancer survivors and caregivers. However, I reached meaning saturation for Themes 1 & 3 after seven interviews, and reached meaning saturation for Theme 2 after nine interviews (Hennick et al, 2017). Samples sizes of approximately 10 participants may be appropriate for sampling a geographically and culturally homogenous population, and smaller sample sizes support comprehensive, in-depth analysis of a phenomena (Boddy, 2016). Therefore, the sample size of 11 was appropriate for providing a comprehensive understanding of resilience in rural cancer survivors.

# Synthesis of findings and clinical implications

The evidence-based conceptual framework of rural resilience can guide nurses to implement geographically-accessible, culturally-appropriate interventions for rural survivors targeting resilience in rural cancer survivors (**Figure**). To strengthen resilience, nurses should consider rural survivors' cultural needs. For example, nurses should consider implementing a spiritual assessment for rural survivors, and advocate for the healthcare team to incorporate spiritual interventions when appropriate. Nurses should also be aware that rural cultural norms of fatalism, cultural differences and mistrust of local hospitals are barriers to resilience that may reduce rural survivors' health-seeking behaviors. If a rural survivor expresses facing a barrier to resilience, such as a spiritual barrier related to fatalism, nurses can offer a spiritual intervention

such as a chaplain consult.

Our findings indicate some rural survivors find virtual platforms to be geographically-accessible and culturally-

Guide survivors to existing virtual support groups and community places with broadband CAPITAL Virtual Networks CAPITAL Virtual Networks CAPITAL Virtual Networks CULTURAL NORMS Trust in God Training in Cultural Sensitivity

Assess for CRD through telemedicine Quality of Life

Figure. Dissertation implications

appropriate. Nurses can implement interventions promoting resilience and reducing CRD

accessible through virtual platforms, especially during the pandemic. For example, because rural cancer survivors prioritize sharing their CRD with a nurse, and are willing to overcome technology barriers to speak with a nurse via virtual platforms, nurses can recommend survivors try existing chat-based virtual support groups and provide a list of them to rural cancer survivors. By guiding survivors to existing support groups to strengthen resilience, and by evaluating CRD via telehealth, nurses may be able to significantly improve rural survivors' QoL.

However, these interventions require nurses to be aware of digital challenges, and to be trained in cultural sensitivity and patient-centered care. At this time, cultural competence in nursing is poorly understood, and there is little evidence-based guidance for cultural training in nursing (Sharifi et al, 2019). Furthermore, rural cultural interventions may conflict with hospital system policies and practices (Farmer et al, 2012). More research is needed to inform nurses education in cultural competence (Young et al, 2020). Regarding digital challenges, nurses need education on the unique rural challenges of accessing virtual platforms, and potential solutions. For example, nurses can have a list of chat-based support groups, so survivors can access the support group whenever they have internet connect (ex: at work). Nurses serving rural populations should have a list of community locations with broadband and digital devices, such as local libraries (DeGuzman et al, 2021).

#### Next steps and directions for future research

This dissertation is the foundation of a program of research that focuses on improving QoL by managing CRD and promoting resilience. Moving forward, there are two more papers to publish from the qualitative descriptive study discussed in Chapter 4. I interviewed rural survivors and caregivers in that study, and found that caregivers are experiencing significant challenges to supporting their own resilience. This finding is critical, because interventions

targeting resilience in cancer survivors often incorporate family and community caregivers (Li et al, 2019). In fact, social support may be one of the strongest facilitators of resilience in cancer survivors (Seiler & Jenewein, 2019). I have performed a secondary analysis of the data with the research question what are barriers and facilitators of resilience for rural caregivers of cancer survivors? In our analysis, I found that female support networks, faith, gratitude for being able to help facilitate resilience, while accommodating rural culture norms for women, mental health stigma, and lack of professional support are barriers to resilience. I am finishing the draft for this paper, and will submit to the Journal of Rural Health in April 2022. I also found that rural cancer survivors and caregivers do trust local providers and nurses, although they mistrust local healthcare facilities. I did a secondary analysis with the research question what is the role of local community healthcare workers to strengthening resilience in rural cancer survivors and their caregivers? In our analysis, I found that local clinicians are considered part of trusted rural community networks, and that they help rural survivors and caregivers navigate complex healthcare systems. I also found that rural caregivers may be open to accepting mental healthcare from local clinicians. I plan to submit this manuscript to the Clinical Journal of Oncology *Nursing* in May 2022.

The next steps in this program of research will be to illuminate how rural cultural and geographic contexts impact CRD symptom experiences of rural cancer survivors and their caregivers in my postdoctoral position. To do this, I will be conducting a secondary analysis of 2,000 rural and urban cancer survivors to identify differences in symptom clusters. I will also be working on a study implementing a telehealth intervention to improve outcomes for rural cancer survivors. After completing my postdoc, I plan to be an independent investigator at a research-

intensive university researching culturally-appropriate, geographically-accessible interventions for rural cancer survivors that improve QoL, reduce CRD and promote resilience.

Within the next five years, I anticipate further examining the role of spirituality in strengthening resilience and reducing distress for rural cancer survivors. The findings of this dissertation indicate spirituality is a critical facilitator of resilience, but that spirituality is not well incorporated into survivorship care. Future research is needed to understand how to appropriately integrate spirituality into survivorship care.

# **Chapter 6 References**

#### References

- Boddy, C. R. (2016). Sample size for qualitative research. *Qualitative market research: an international journal*, 19(4), 426-432. Doi.org/10.1101/QMR-06-2016-0053
- DeGuzman, P. B., Abooali, S., Jain, N., Scicchitano, A., & Siegfried, Z. C. (2021). Improving equitable access to care via telemedicine in rural public libraries. *Public health nursing* (*Boston, Mass.*), 10.1111/phn.12981. Advance online publication. https://doi.org/10.1111/phn.12981
- Farmer, J., Bourke, L., Taylor, J., Marley, J. V., Reid, J., Bracksley, S., & Johnson, N. (2012).

  Culture and rural health. *The Australian journal of rural health*, 20(5), 243–247.

  https://doi.org/10.1111/j.1440-1584.2012.01304.x
- Hennink, M. M., Kaiser, B. N., & Marconi, V. C. (2017). Code Saturation Versus Meaning

  Saturation: How Many Interviews Are Enough?. *Qualitative health research*, 27(4), 591–608. <a href="https://doi.org/10.1177/1049732316665344">https://doi.org/10.1177/1049732316665344</a>
- Li, Y., Qiao, Y., Luan, X., Li, S., & Wang, K. (2019). Family resilience and psychological well-being among Chinese breast cancer survivors and their caregivers. *European journal of cancer care*, 28(2), e12984. https://doi.org/10.1111/ecc.12984
- Mealer, M., & Jones Rn, J. (2014). Methodological and ethical issues related to qualitative telephone interviews on sensitive topics. *Nurse researcher*, 21(4), 32–37. https://doi.org/10.7748/nr2014.03.21.4.32.e1229
- Sharifi, N., Adib-Hajbaghery, M., & Najafi, M. (2019). Cultural competence in nursing: A concept analysis. *International journal of nursing studies*, *99*, 103386. https://doi.org/10.1016/j.ijnurstu.2019.103386

- Seiler, A., & Jenewein, J. (2019). Resilience in Cancer Patients. *Frontiers in psychiatry*, 10, 208. https://doi.org/10.3389/fpsyt.2019.00208

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Proposal was formatted to meet NINR guidelines for an F31 submission.

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